

Design Your Discussion

From symptoms, to treatment, to goals, navigating the role of a parent/caregiver of a child with narcolepsy may feel like a lot to juggle. Take time to reflect on your and your child's wants and needs, and use this guide to help prepare for the next appointment with your child's healthcare provider.

Dig Into the Details

Take a moment to answer the questions below and consider what may be getting in the way of managing your child's excessive daytime sleepiness (EDS) in narcolepsy.



1

In my child's day-to-day routine, EDS in narcolepsy
(mark all that apply)

- ☐ Makes it harder to maintain relationships or a social life
- ☐ Creates challenges when it comes to school
- ☐ Affects my child's daily activities or routine
- ☐ Other: _____

2

How would you feel if your child's EDS in narcolepsy was better managed?

3

When it comes to treatment for my child, I am
(mark all that apply)

- ☐ Frustrated with their treatment because _____
- ☐ Having a hard time finding what works for them
- ☐ Concerned about stimulants or the potential for abuse
- ☐ Other: _____

4

What do you want out of a treatment for your child's EDS in narcolepsy?

Put It All Together Nice work! You've thought about what may be in the way when it comes to your and your child's wants and needs for managing EDS in narcolepsy. Now, put it all together so that you can share it with your child's healthcare provider at their next appointment.



Today, I'd like to talk with you about how my child is doing and how to help my child get closer to where we'd like to be. In my child's day-to-day routine, EDS in narcolepsy _____
[use your answers from 1]

If my child's EDS in narcolepsy were better managed, I'd feel _____
[use your answer from 2]

When it comes to my child's treatment, I am _____
[use your answers from 3]

I want _____ from a treatment for EDS in narcolepsy. I'd like to talk
[use your answer from 4]
about treatment options for my child.

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Here are a couple of questions you may want to ask your child's healthcare provider. You can also write in some of your own questions on the lines below.

- What treatment options are available for my child?
- How might those treatment options help us get closer to where I want my child to be?

My questions are:

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Keep Talking Take this guide with you to your child's next appointment. Continue the conversation with your child's healthcare provider about what you want out of a treatment for your child's excessive daytime sleepiness (EDS) in narcolepsy.



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