narcolepsy

nerd alert

PREGNANCY & NARCOLEPSY TOOLKIT

Created by:

projectsleep

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TOOLKIT INDEX

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 pregnancy with 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. Special guests from the sleep community join us for 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 throughout the toolkit are from panelists and audience members 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.

MEET OUR PANELISTS

Diana Anderson, PA-C lives in Knoxville, TN, and was diagnosed with narcolepsy type two at the age of 34. She had symptoms for 10 years before receiving the diagnosis of narcolepsy. She has a 4-year-old son and works full time as a physician assistant. Diana is a dedicated advocate for individuals with sleep disorders and a trained speaker for Rising Voices with Project Sleep.

Emily Barker, PhD is originally from Utah and now lives in Cleveland, OH. She has narcolepsy with cataplexy and is the mom of three boys (ages 11, 9, and 4). Emily deeply enjoys connecting with other parents as a co-facilitator for the Wake Up Narcolepsy Pregnancy and Parenting with Narcolepsy peer support group. Emily is also a scientist and a medical writer. She enjoys music, the outdoors, and playing sports with her kids.

Dr. Anne Marie Morse, DO is a board-certified and fellowship-trained pediatric neurologist specializing in sleep medicine at Geisinger Health System in Pennsylvania. Her clinical interests include sleep-wake disorders in neurologic disease, narcolepsy and hypersomnia disorders, and neuroimmunology. Her research interests include sleep-wake disorders in neurologic disease, hypersomnia disorders, and sleep-wake disorder phenotyping.

Ashley Nutter, MEd lives in Burke, VA with her husband and three children. At age 19, Ashley was diagnosed with narcolepsy with cataplexy while attending George Mason University. Despite battling sleep and health issues, she did exceptionally well academically and in addition to a Bachelors degree in Psychology, Ashley holds a Masters in Education Community Agency Counseling from GMU.

Katie Williamsen is a mom to one daughter, yoga enthusiast, and web designer living in Missouri. She was diagnosed with narcolepsy with cataplexy at the age of 29. Katie is a trained Rising Voices speaker and shares her story to raise awareness of this life-altering condition.

Michelle Zagardo is a photographer, teacher, and gummy bear enthusiast living in Connecticut. She was diagnosed with narcolepsy with cataplexy at age 28 (approximately 20 years after symptom onset) and has a 6 month old daughter. Michelle is a speaker through Project Sleep's Rising Voices program and maintains a blog (michellezagardo.com) and instagram account (@michellezagardo) that frequently address narcolepsy. You can also follow Michelle's service dog on IG @olivebug__.

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.* She is also an avid runner and tennis player living in Los Angeles, CA.

PREGNANCY & NARCOLEPSY

Thinking about starting a family while living with narcolepsy?

You are not alone! Like many people with narcolepsy thinking about starting a family, you may have questions about how to manage narcolepsy's symptoms and treatments during this process. Questions we often hear from our community:

- *How should I adjust my medications during preconception, pregnancy, and postpartum?*
- *What is the likelihood that my child might also develop narcolepsy?*
- *What kinds of healthcare providers should be involved?*
- *How have other people with narcolepsy managed?*
- *What about adoption as an option?*

This toolkit aims to address common questions, provide the current scientific data and resources, and share real-life experiences from people who have walked this journey. Our panelists' experiences vary, which is an important reminder that **there is no "one-size-fits-all" approach to starting a family.** We hope this toolkit is empowering in providing introductory information, ideas, and resources as you begin this exciting next chapter in your life!

Project Sleep developed this toolkit following our "Pregnancy & Narcolepsy" broadcast on January 27, 2022.

- Watch the Pregnancy & Narcolepsy Video
- Learn more about the Narcolepsy Nerd Alert Series

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YOUR ALL-STAR SUPPORT TEAM

Pregnancy and symptom management for people with narcolepsy requires collaboration and communication between the parents-to-be, specialized health care providers, and others. A team approach will help set expectations and allow for shared decision-making.

- **The pregnant person** is the captain of the team, calling the shots and utilizing the rest of the team's expertise and support to be well-informed about all important decisions.
- **The pregnant person's partner or other support person** should be included in discussions about risks and benefits of decisions that may impact the family.
- **The sleep doctor** should be closely involved and provide education and consultation on narcolepsy management options, including detailed medication and behavioral strategies.
- **The obstetric doctor or equivalent pregnancy or birthing support** should be in regular communication with the sleep doctor to facilitate clear understanding of expectations and the reasoning behind narcolepsy management decisions.
- **Social support** is an invaluable resource for many parents-to-be with narcolepsy. Hearing from other parents with narcolepsy and sharing experiences and concerns can be empowering and grounding. See page 24 for social support resources.

Additional specialists to involve if you have other health conditions or concerns after meeting with your sleep & obstetric doctors:

- **A maternal fetal medicine specialist,** often referred to as the "high-risk" doctor, is trained to take care of individuals who have medical conditions or high-risk pregnancy conditions that could impact the length of pregnancy, the health of the pregnant person, or the health of the baby.
- **A genetics counselor** may be consulted to help identify any hereditary health concerns and suggest avenues to prepare for or mitigate risks to the baby's health.

Pro tip: bring notes, take notes

Before seeing your providers, write down specific questions or print our list of Questions for You & Your Providers on page 8. Bring contact information for other providers who will be on your medical team. During the visit, take notes and write down other questions that come up. If you experience brain fog or memory issues, consider bringing your partner or a loved one with you to these appointments, or calling them on speaker phone to join the meeting.

QUESTIONS FOR YOU & YOUR PROVIDERS

There are varying degrees of familiarity with narcolepsy in the medical field. The questions below are prompts for you and your providers in pregnancy planning.

Print this page to review with your providers.

Questions you may want to ask your doctors:

- Do my medications impact birth control?
- Have you worked with parents-to-be living with narcolepsy or other complex neurological conditions through a pregnancy?
- What are the risks of the medications I am on during pregnancy? Do risks differ by trimester?
- What do you see as potential risks of adjusting or stopping my treatments through this process?
- How will my symptoms be managed throughout pregnancy? How might we adjust if the severity of my symptoms changes?
- Are there trimester-dependent risks to the fetus due to medication exposure or increased potential harm due to a fall?
- Who else should be on my medical team? Should a maternal-fetal medicine specialist be included based on my medications and diagnosis?
- For my birth plan, if my symptoms (excessive sleepiness, cataplexy) present severely during labor, how would this be managed? How can I optimize my chances of a successful vaginal delivery?
- How can I optimize my safety and my baby's safety during the postpartum period?
- If I choose to breastfeed, what are potential risks of my medication for my baby?
- Can I help answer any questions or provide any additional information about narcolepsy or my experience with narcolepsy?

Questions your doctors may ask you:

- What symptoms do you use medication to manage? Are you familiar with any non-medication strategies to manage symptoms during pregnancy?
- What are your thoughts about continuing medication during pregnancy?
- What additional strategies can we employ to optimize your physical and mental wellness?

CONSIDERING POTENTIAL RISKS

Throughout the entire family planning process, there will be many decisions to make, including how to manage narcolepsy symptoms and medications.

Healthy pregnancies and babies are always the goal, so it is important to contemplate all risks to the pregnant person and unborn baby. While potential risks of **medications** on a fetus's development are often top of mind and an important consideration, **untreated narcolepsy** may present potential risks as well.

KEY TAKEAWAY: Potential risks to the unborn baby from medications must always be balanced with potential risks of untreated symptoms to the unborn baby and the pregnant person.

While narcolepsy symptoms are often invisible and hard for outsiders to understand, untreated symptoms have varying impacts on safety, daily functioning, and abilities to fulfill responsibilities. Further, the pregnant person's physical, emotional, *and* psychological wellbeing are all important.

Each person's experience with narcolepsy is different, and each pregnancy is different. Some people find that narcolepsy symptoms actually improve during pregnancy, while others have the opposite experience. Things may change over the course of the pregnancy too.

You may not be sure how your body will respond to pregnancy and medication changes. On the next page, we've offered some discussion questions to help think through the possibilities.

> If a pregnant patient has untreated narcolepsy and they're having severe symptoms — excessive daytime sleepiness which is compromising their reaction time, or severe cataplexy which is causing them to fall, or automatic behaviors doing things that they're unaware of and putting themselves at risk — you are doing them and their baby a disservice by not discussing treatment options.
>
> - Dr. Anne Marie Morse

CONSIDERING POTENTIAL RISKS

Here are some questions to ask yourself or to explore with your partner or a loved one when considering risks and benefits of medication during pregnancy:

- What are my most severe symptoms with and without medications? (cataplexy, excessive sleepiness, brain fog)
- Have I ever gone off of medications before? How did this go?
- Are there potential safety risks for me or my baby if I am experiencing severe symptoms without treatment?
- If I were to adjust or go off of medications, what are some foreseeable impacts on my daily activities and responsibilities (e.g., will there be changes in my ability to drive, work, or care for family members)?
- How might we work through any shifts in my abilities?
- Who is on my support team? Are there individuals or support resources to ask for help during this time?
- Have I connected with other people with narcolepsy who have walked this path to ask questions and gather practical tips?

> When researchers survey people with narcolepsy who have experienced pregnancy, there are people who have stayed on their medication. In fact, when researchers compared these people to those who stopped their medication, they found no major differences in terms of the pregnancy outcomes, the modes of delivery, how the baby did, or anything else.
>
> Source: Pascoe et al., 2019
>
> - Dr. Anne Marie Morse

MEDICATION AND PREGNANCY

What are the possible effects of taking medication while pregnant?

Below is a summary of current evidence regarding the potential risks of some medications used to treat narcolepsy. It's important to have a detailed discussion with your doctor about what this means for YOU.

OXYBATE

Animal studies have shown no evidence of teratogenicity. Data from a limited number of pregnant patients exposed in the first trimester indicate a possible increased risk of spontaneous abortions. Limited data from pregnant patients during second and third trimesters did not indicate malformative or fetal/neonatal toxicity of this drug (Xyrem, 2021).

WAKE PROMOTING AGENTS

Intrauterine growth restriction and spontaneous abortion have been reported with modafinil and armodafinil. Some animal studies have revealed embryofetal toxicity and lethality in the absence of maternal toxicity at clinically relevant exposures, while others demonstrated no adverse effects on embryofetal development (Nuvigil, 2017).

When used during pregnancy, modafinil and armodafinil have been associated with cases of major fetal congenital malformations, including congenital cardiac anomalies (Health Canada, 2019; Miller et al., 2020).

SOLRIAMFETOL & PITOLISANT

There is insufficient data to determine drug-associated risk for adverse maternal or fetal outcomes with solriamfetol or pitolisant use in pregnancy (Sunosi, 2021; Wakix, 2021).

STIMULANTS

Stimulants in general can cause vasoconstriction which would decrease placental perfusion (Ritalin, 2021).

METHYLPHENIDATES

Published studies and postmarketing reports are insufficient to inform a drug-associated risk of of major birth defects, miscarriage, or adverse pregnancy-related outcomes; based on animal data, this drug may cause fetal harm (Ritalin, 2021).

AMPHETAMINES

Premature delivery, low birth weight infants, and neonatal withdrawal have been reported in amphetamine-dependent patients (Dexedrine, 2020).

ANTIDEPRESSANTS

SSRIs, SNRIs, and tricyclic antidepressants have been associated with premature birth, low birth weight, intrauterine growth restriction, vasoconstriction, neonatal adaptive syndrome, and pulmonary hypertension. Some risks may be trimester dependent. Risks for congenital malformations with antidepressant use in pregnancy are considered small (Dubovicky et al., 2017; Miller et al., 2020).

Note that often this data comes from **animal studies**, and the dosing is sometimes 10, 15, 20, or even 40 times the dosing (by body weight) that would be used for humans.

OUR STORIES

Some people may conceive right away, however the duration of the preconception period can **vary widely**; up to two or more years. Thus, any adjustments to one's narcolepsy treatment during preconception should be an individualized discussion between each person and their medical team.

- Michelle used ovulation strips to check for ovulation so that she wouldn't have to discontinue medication before conception. She says, "It took us **about a year to conceive** and doing that without medication would have been brutal for me."
- Emily says, "We had **no idea how long conception would take**, and it didn't feel sustainable to be off of medication at times when we didn't know if pregnancy was even a possibility."

Emily and her husband Sam love getting outdoors as a family in all seasons.

In discussion with their doctors, some panelists felt that preparation for pregnancy was prioritized above narcolepsy management.

- Ashley commented that during her pregnancies, "talk about narcolepsy was **put on the back burner** because they were more focused on the health of the baby and some of my other health issues."
- When Diana was diagnosed with narcolepsy, she was recently married and knew she wanted to start a family. Her sleep doctor said, "You're going to try to get pregnant? You need to stop modafinil a month before."

> Pregnancy is not one-size-fit-all. In fact, narcolepsy alone is not one-size-fits-all, so when we are adding layers we need to make sure we're tailoring decisions to the person in front of us.
>
> - Dr. Anne Marie Morse

Michelle made it a priority to find a neurologist who specialized in pregnancy. This doctor spearheaded her care, and with his supervision she made the decision to stay on Xyrem throughout preconception and pregnancy at a slightly lower dose.

> I had this idea that it was 'virtuous' to be unmedicated during pregnancy, but it was not realistic for me.
>
> - Michelle

Michelle's husband Darrell takes a family selfie on one of their first hikes with baby Hadley.

Ashley felt that being on any medication while pregnant was "out of the picture." She was able to manage her symptoms with naps during her first pregnancy. She experienced severe narcolepsy symptoms during her second pregnancy, but remained unmedicated because of concerns about previous complications.

> I have really bad cataplexy so I was concerned about that, especially with driving. And sometimes my mind would go blank and I wouldn't know where I was.
>
> - Ashley

Ashley and her family enjoy a unicorn party.

Diana remained off of her narcolepsy medication throughout her pregnancy and continued working as a surgical physician assistant. She explains, "after our morning cases, before afternoon clinic, I would sometimes go into my office which just conveniently had an exam table, and I would take a snoozer." The naps were just enough to get her through her work day, but afterwards "I really felt the effects — I was done for the rest of the day, just so tired." People sometimes describe feeling forgetful while pregnant, often called "pregnancy brain." Diana admits, "I had that to the 10th or maybe 20th power."

Diana and her husband Ryan on vacation while she was pregnant with their son.

Emily has had three children. With her first pregnancy, she stopped taking medication at the time of conception. She says, "I ended up feeling better than I thought I would and was able to manage fairly well with naps."

Following her second pregnancy, Emily was unmedicated and breastfeeding and taking care of a growing toddler. Due to a small age gap between children, Emily did not take medication for about 36 months. She says, "It is hard to remember much about those years, but I know they were exhausting." After her third son was born, Emily resumed some of her treatment and adjusted her breastfeeding to limit his exposure to medication that could be in her breast milk. The difference was stark. She recalls finding herself "more wakeful, more confident for driving, more productive, more present-minded, and gentler with [herself] and others" compared to her prior experiences.

> My cataplexy triggers have changed with the new emotions of motherhood. I remember collapsing to the floor in a moment of exasperation during the third trimester of my third pregnancy. Considering the potential for injury and unpredictable nature of cataplexy, we determined at that time to consider medication more seriously in the event of a future pregnancy.
>
> - Emily

TIPS DURING PREGNANCY

If you choose to adjust, reduce, or stop medications during pregnancy, some coping strategies may be helpful. What works for each person varies; here are some ideas from our panelists:

- **More naps, less guilt.** Your body is spending a lot of energy on building the baby, and you shouldn't feel bad for taking naps and prioritizing your wellbeing.
- **Movement is a good way to maintain alertness.** Work standing up, take breaks, walk around. If you have conference calls, join them while walking if possible.
- **Consider requesting accommodations** (formal or informal) at work or school.
- Try to **anticipate cataplexy triggers and sit down.** If possible, let a support person/partner know when cataplexy triggers may be present.
- Don't stress about buying every piece of "baby gear" you think you may need. Katie says, "When a baby first comes home from the hospital, they don't need that much. There are endless nice-to-have items, but there are *just a few essentials you must have*."
    - Diapers and wipes
    - Bottles
    - A breast pump or formula
    - Pajamas/sleepers
    - Car seat
    - Swaddle/wearable blanket
    - A place to change diapers that's safe and comfortable for you and your baby. Don't kill your back changing diapers on the floor or bed!
    - A bassinet/safe place for the baby to sleep. Parents often have the baby sleep in the bedroom with them for the first few months and don't need a fully furnished separate nursery.
    - A carrier to "wear" the baby on your chest, while not essential, can be a game-changer for your ability to move around while keeping your baby comfortable and happy.

PLANNING FOR YOUR BABY'S BIRTH

It's important to discuss a **birth plan** for your specific needs with your birth care providers. It can be empowering to talk about your preferred method of delivery, and how your team will respond if narcolepsy symptoms present severely or in other unforeseen circumstances.

- It's natural to have concerns about whether you will deliver vaginally or via cesarean section. Ask your obstetrician or other birth provider, "If cataplexy or excessive daytime sleepiness present while I'm in labor, how would this be addressed?"

- While vaginal delivery is the most common outcome, having narcolepsy does slightly increase the likelihood of needing a c-section.
  - Remember that having a c-section is a brave & difficult thing to do — it should not be seen as a failure in any way.

- While your sleep specialist is not involved in the actual delivery, they may be able to provide some strategies to maximize your chances of a vaginal delivery, if that is what you want.

- It's a good idea to have a **hospital bag** packed well before your due date and keep it with you at all times.
  - Make sure to have a **copy of your birth plan** in the bag.
  - Some comfort items you may want to include: shower shoes, a towel, a change of clothes, a pillow, headphones, glasses.

- When you arrive at the hospital, make sure the people caring for you (especially nurses) are aware of your narcolepsy diagnosis. While it's probably in your medical notes, they may not see it or may not be familiar with narcolepsy. In this case, a knowledgeable support person can be helpful.
  - Ashley was unintentionally wearing a World Narcolepsy Day shirt when she went to the hospital to deliver her third child. She says that wearing the shirt actually prompted conversation about narcolepsy with the nurses, which made her feel more comfortable.

POSTPARTUM

The first few weeks and months with a new baby can be emotionally and physically exhausting for many people. The impact of sleep deprivation may be especially acute for new parents with narcolepsy, particularly for those who choose to reduce or discontinue medications for reasons related to breastfeeding.

Breastfeeding has many advantages such as boosting the newborn's immune system and facilitating bonding between the parent and baby. For these reasons, some parents choose to breastfeed while taking certain medications for narcolepsy. While larger studies are needed to fully understand the risks, there are strategies to potentially minimize the baby's exposure (see pages 20-21). **A lactation consultant or postpartum doula** can provide support for breastfeeding and help you find additional resources.

While having "baby blues" is a common experience, new parents with narcolepsy may have additional challenges adjusting to life with a newborn.

- According to the National Institute of Mental Health, "The 'baby blues' is a term used to describe *mild* mood changes and feelings of worry, unhappiness, and exhaustion that many people sometimes experience in the first two weeks after having a baby. Babies require around-the-clock care, so *it's normal for people to feel tired or overwhelmed* ***sometimes***. If mood changes and feelings of anxiety or unhappiness are severe, or if they last longer than two weeks, a parent may have postpartum depression."
- Untreated symptoms of narcolepsy may also contribute to feelings of helplessness and despair. If the condition is getting in the way of your ability to be the parent you want to be, your treatment plan should be reevaluated.

Couples counseling can help with communication as parents navigate responsibilities and sleep deprivation. Michelle says, "When we were eight months pregnant, my husband and I started couples counseling with a counselor who specialized in postpartum and chronic illness. It really helped to know that someone else was on our team."

Nighttime responsibilities with a newborn can be difficult, especially if you are not taking medication. Diana did not take medication during lactation, and shares a moving story about how, late one night when it was her turn to feed her infant son, she ended up dozing off accidentally. Upon waking up, her baby's body had moved slightly into a position that could have been dangerous. This was a scary experience and "aha" moment for Diana, inspiring her to change course. She says, "I stopped breastfeeding and got back on medication, so I could be awake and be there for my son."

TIPS FOR WHEN BABY ARRIVES

If you choose to adjust, reduce, or stop medications during the postpartum period, there may be some coping strategies that could help you manage during this time. Panelists and parents attending the Pregnancy and Parenting with Narcolepsy Peer Support Group provided some helpful ideas for adjusting to life with a newborn:

- **Have multiple safe areas** where you can quickly and easily set the baby down, if needed. (e.g., floor bouncer, swing).
- **Prioritize YOUR health and nutrition:** caring for others starts with caring for yourself. Ready-to-go meals are key for getting enough nutrition with limited time and energy.
- **Take inventory of sleep needs.** You and your partner or supporter may need different hours of sleep, or to sleep in separate spaces to avoid disturbing each other's sleep (e.g., when one of you is getting up to care for your baby).
- **Be honest about how much sleep you're getting,** with yourself and your support person/partner. You may feel refreshed (comparatively) after an hour nap but still be mentally and physically exhausted.
- **If someone offers to help you, say yes.** An hour of child care, a home cooked meal, or a trip to the grocery store could be just the break you need.
- **Write a list of every support person you could possibly call:** people who can bring you food, people who can take the baby if you need a nap. Rank them from your first choice to your last choice and hang it on the fridge. You may never need it, but seeing the list can remind you that you have a support system if things get tough.
- **Don't be shy to ask for help with house tasks** when friends or family visit.
- **Ask friends or family to check in regularly.**
- **Think outside the box:** neighbors or colleagues may be interested in lending support.
- Consider hiring a **postpartum doula** to help your family get settled with the baby (including for nighttime support).
- If you have multiple children, there's no shame in getting **outside help with child care** (in-laws, babysitter, after-school care) if this is accessible to you.
- Consider other **temporary hired help,** if feasible (e.g., dog walking, house cleaning, pre-made meals, or laundry help).
- Find small moments of **alone time** — a shower with essential oils, a few minutes to scroll on your phone — and trade with your partner or supporter so that you both get time to recharge.
- **Get outdoors.**

- **Consider positioning for feeding times:** place safety measures (e.g., supportive pillows to keep yourself upright) to protect the baby in an event of inadvertent sleep.
- **Be open to formula-feeding** to allow others to feed your baby while you rest. Weaning to resume certain medications may help overall wellness. Remember there is no pressure to breastfeed for a prolonged period.
- If you are formula feeding the baby, **have bottles ready to grab out of the fridge** for middle-of-the-night feedings. You can use a bottle warmer or a bowl of warm water to warm the formula.
- If you choose to breastfeed, **set a vibrating alarm** to keep yourself from dozing off, while also not waking the baby. You could also keep **snacks and water** close by.
- **Save some shows you want to watch** for this time, or find fun content that keeps your interest to maximize your alertness while feeding the baby.
- If possible, work with a partner or other support person to **share nighttime feeding duties** (e.g., a partner can manage diapering, burping, and bringing and taking the baby).
- Finding the right **schedule for breastfeeding and pumping** can be a challenge. Try not to compare yourself to other parents – it's important to find the schedule that works for YOU, and bring any questions directly to your doctor or lactation consultant.
- **Place a small refrigerator in the bedroom** to store milk and pumping supplies.
- If you struggle to stay awake for nighttime feedings, you could use a **co-sleeper bassinet,** which attaches to the side of your bed, so you can safely put your baby down without having to stand and carry them across the room.
- Consider a **soothing bassinet** (e.g., Snoo) if you are concerned you will fall asleep soothing your baby.
- If possible, let a support person/partner know when **cataplexy triggers** may be present, keeping in mind that the new emotions with parenthood could become additional triggers.
- **Find a bathtub that you can comfortably hold the baby in.** A tub with knee and elbow rests might help minimize the risks of partial cataplexy, but sometimes it's best to let your partner/support person take over.
- **Early light exposure** and **daily walks** can be helpful for symptom control when on reduced medication.
- **Try to nap when the baby naps** and when support people are available to help with the baby.
- **Set manageable goals** to do 1-3 things during the day. An appointment with your baby counts as one big thing!
- **Mental health professionals,** if accessible to you, can be great resources. A couples counselor may help you and your partner thrive during this transitional period, or you could look for a therapist who specializes in postpartum counseling.
- **Seek help before you absolutely need it.**

MEDICATION DURING LACTATION

What are the possible effects of taking medication while breastfeeding?

Below is a summary of current evidence regarding the potential risks and strategies for breastfeeding while on medication. It's important to have a detailed discussion with your doctor about what this means for YOU.

OXYBATE

Detected in breastmilk after oral administration. Sleep pattern changes in breastfed neonates have been observed (Xyrem, 2021).

Options for decreasing potential oxybate exposure to the neonate include avoiding breast feeding between nighttime doses and discarding milk expressed within 6 hours of dosing (Barker et al., 2017).

WAKE PROMOTING AGENTS

There is minimal data on the presence of wake promoting agents in human milk and their effects on breastfed infants. When administered in lactating animals, these agents have been detected in animal milk and are likely present in human milk. Benefits of breastfeeding should be considered as well as clinical needs of the mother and any potential adverse effect on the breastfed child from the drug or from the underlying maternal condition. (Modafinil, 2011; Thorpy et al., 2013).

STIMULANTS

Breastfed infants should be monitored for adverse reactions, such as agitation, insomnia, anorexia, and reduced weight gain. Long term neurodevelopmental effects on infants from CNS stimulant exposure are not known (Ritalin, 2021).

> There is the potential for narcolepsy medications to be in breast milk. It is important to have a conversation with your provider about strategies to be able to continue using medications while breastfeeding.
>
> - Dr. Anne Marie Morse

Lactation information for specific medications

The National Institute of Health's LactMed® database contains information on drugs and other chemicals to which breastfeeding parents may be exposed. It includes information on the levels of such substances in breast milk and infant blood, and the possible adverse effects in the nursing infant.

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OXYBATE EXCRETION IN HUMAN MILK

Emily, one of our panelists, is a scientist and medical writer. She stayed off of medication through breastfeeding with her first two children, but knowing that sodium oxybate is in the bloodstream for a limited time period, she wondered how it would show up in breastmilk. She explained, "I actually worked in a lab where we studied these molecules and I had a lab mate who worked on oxybate. So I knew we had all the tools." Emily connected with a clinician/researcher at Brown University, Dr. Katie Sharkey, who was also interested in doing a similar study. The following research on sodium oxybate in breastmilk is a product of their collaboration.

The research participants, two mothers with narcolepsy with cataplexy, pumped milk at timed intervals. The researchers analyzed how much sodium oxybate was in the milk in the hours after taking oxybate medication.

- Sodium oxybate is an endogenous (produced by the body) molecule found in many of our tissues (Busardò et al., 2016), so there was a **baseline value** of sodium oxybate in milk before taking sodium oxybate medication.
- While the sodium oxybate medication was in effect, the milk produced did have more sodium oxybate (Barker et al., 2017).
- Six hours after the second dose of medication, the amount of sodium oxybate in milk returned to baseline.

This suggests that **breastfeeding people receiving oxybate therapy may be able to schedule nursing** to avoid potential oxybate exposure to infants through milk. Such an option should be discussed with your treatment team (patient, obstetrician, and sleep specialist) in planning the medication regimen for lactation.

> It is critical to maintain patient empowerment by encouraging shared decision-making. This should not be a unilateral conversation where the provider is dictating one option.
>
> - Dr. Anne Marie Morse

ADOPTION

Adoption may be another route to starting a family. Katie shared her journey to parenthood via adoption.

If you are considering growing your family via adoption, start by learning about your options and connecting with others who have adopted. The two main ways to adopt in the U.S. are via an agency or private attorney.

The adoption process will be different for everyone, whether you choose to adopt locally, statewide, or internationally. No matter what type of adoption you choose, you must have a home study completed by an accredited adoption professional. The home study includes an assessment of the home by a social worker, background checks, and a medical exam by a primary care physician.

> The adoption agency wasn't that concerned about my narcolepsy, but they weren't familiar with it. Their question was, 'Are you going to be okay to parent?' So my sleep medicine doctor wrote a short note basically saying, 'Katie can parent with narcolepsy.'
>
> - Katie

Katie and her husband Chad chose to adopt for many reasons. Katie says, "Chad's sister is adopted and some of my cousins are too, so adoption has always been part of our lives. When it came to creating a family, I knew I would not be able to stop taking my medication because my cataplexy is severe. I also didn't want to risk my cataplexy worsening if I became pregnant."

The adoption process took over two years for Katie and Chad. Katie says, "We didn't know when we were going to have a child come into our lives. With adoption, in a perfect scenario you'd have about three months notice — we had about six hours notice. We got a call on a Saturday morning, and we went to the hospital that afternoon and met our baby."

Katie and her husband with their newborn daughter. Photo by Sketchbook Photography

narcolepsy nerd alert

COULD MY CHILD DEVELOP NARCOLEPSY?

If you have narcolepsy, you may wonder what the chances are of having a child who also develops narcolepsy. Here's what is known about the genetic factors of narcolepsy:

- Most cases of narcolepsy are **sporadic**, meaning they happen randomly with no family history of narcolepsy.
- When there is a familial pattern, it tends to be **first-degree relatives** that are affected. In different parts of the world where this has been studied, the frequency of narcolepsy in first-degree relatives varies (Chen et al., 2007).
- It is estimated that if you have type 1 narcolepsy with cataplexy (NT1), the chances of having a child with narcolepsy would be between **1-2%, or 1-2 out of 100**, compared to a general population chance of 0.02-0.08% (Mignot E, 1998).
- It is believed that this chance is lower (or less likely) for people with type 2 narcolepsy without cataplexy (NT2). In general, less is known about what genetic or other factors lead to the development of NT2 in certain individuals.

While some traits are passed down through traditional *mendelian inheritance*, type 1 narcolepsy is different and likely related to **HLA inheritance**.

Although in type 1 narcolepsy there is a specific gene typically present (HLA-DQB1*0602), this is a ***risk gene*** — 25% of the general population carries this gene but don't all have narcolepsy (Mignot E, 1998).

Weighing potential risk factors is a personal, individualized choice. For our panelists, many expressed that they believe their own experience with narcolepsy has prepared them to be strong advocates and supporters, if their child does develop narcolepsy.

See our Science of Narcolepsy Nerd Alert for an in-depth explanation of genetic factors.

> “I’m confident that because I have narcolepsy and my husband and I are on top of it, my son would have the best support ever if he developed it.
>
> - Ashley

SOCIAL SUPPORT

Connecting with other parents and expecting parents who also live with narcolepsy is invaluable. After identifying few resources for support during her pregnancies, Emily was thrilled to partner with Wake Up Narcolepsy to form the online support group: **Pregnancy and Parenting with Narcolepsy**.

> Getting involved with Wake Up Narcolepsy's Pregnancy & Parenting support group was a game-changer in helping me navigate my first pregnancy with narcolepsy.
>
> - Michelle

- Find the **Pregnancy & Parenting with Narcolepsy Online Support Group** by subscribing to Wake Up Narcolepsy on HeyPeers.com.
  - Group meetings are held weekly.
  - Topics covered during the repeating 6-week sessions include:
    - Narcolepsy before the baby (sleep and OB prenatal consultations, preconception and medications)
    - The role of partners and other support
    - Narcolepsy and pregnancy (pregnancy/lactation and medications, symptom management, health care provider collaborations)
    - Narcolepsy with a newborn (labor/delivery, sleep deprivation, safety)
    - The journey of parenthood with narcolepsy (prioritizing mental health, multiple children, talking to children about narcolepsy)
- Support can also be found on social media, including a Facebook group called: **Pregnant People with Narcolepsy (and mothers)**.

> As a group co-facilitator, I hope I can share from my own positive experiences and encourage other parents. I am so grateful for friendships I've formed and to be a part of this invaluable resource of support and connection for parents at all stages of the child-bearing journey.
>
> - Emily

FINAL TAKEAWAYS

"Be kind and patient with yourself... And accept help from others!" - Ashley

"Do NOT be afraid to ask your healthcare provider(s) any questions you may have. If they cannot give you an answer, be sure they direct you to someone who can!" - Diana

"It can be done... There are strategies to make pregnancy with narcolepsy feasible, and even enjoyable." - Emily

"If adoption sounds like a good path for your family, explore it and go for it!" - Katie

"If you are committed to being a parent, there are a lot of ways to do it and take your health into consideration. And there's an awesome community of people here to support you." - Michelle

"I hope you feel empowered and activated in your patient journey to demand the care that you feel you deserve." - Dr. Anne Marie Morse

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ADDITIONAL RESOURCES

In addition to the social support resources listed on page 24, here are some more great resources. We look forward to hearing what you find useful!

PREGNANCY & POSTPARTUM RESOURCES

- Hypersomnia Foundation's Parenthood & Pregnancy page
- Hypersomnia Foundation's Hormonal Therapy, Birth Control, & Menstruation page
- National Institute of Health's LactMed® database
- National Institute of Health's Perinatal Depression page
- Michelle Zagardo's Prepping for Baby with Chronic Illness blog post
- The International Lactation Consultant Association
- DONA International (Information and directory for families considering doula care)

PREGNANCY REGISTRIES

Pregnancy exposure registries monitor pregnancy outcomes in people exposed to certain medications. The purpose of the registries is to **collect data** that will help identify the risks of taking certain medications during pregnancy for future patients.

Pregnancy exposure registries exist for people exposed to psychiatric medications during pregnancy (including methylphenidate and dextroamphetamine), pitolisant, solriamfetol, modafinil and armodafinil. If you are on these medications for any duration of pregnancy, you can consider registering with the help of your doctor or directly through the registry organizations:

- National Pregnancy Registry for Psychiatric Medications: 1-866-961-2388
- WAKIX Pregnancy Registry: 1-877-302-2813
- SUNOSI Pregnancy Registry: 1-877-283-6220
- NUVIGIL/PROVIGIL Pregnancy Registry: 1-866-404-4106

ADOPTION RESOURCES

- New York Times article What to Know Before Adopting a Child
- U.S. Dept. of Health and Human Services' National Foster Care & Adoption Directory
- U.S. Dept. of Health and Human Services' The Adoption Home Study Process factsheet
- Academy of Adoption and Assisted Reproduction Attorneys' Directory
- Human Rights Campaign Foundation's list of agencies committed to non-discriminatory policies
- Adoptive Families
- HelpUsAdopt.org
- National Council for Adoption

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

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THANK YOU!

We are 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

projectsleep

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