

PATIENT EDUCATION

Caregiver Guide

Substance Exposed Newborns (SEN)



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Introduction

Congratulations on the birth or upcoming birth of your baby!

The early moments with your baby can be both exciting and overwhelming. This book will review what to expect with a new baby who may be having symptoms of withdrawal and provides resources that can help you and your baby. This guide can also help others who may care for your baby, like relatives and day care providers.

We all have the same goal – to help you and your baby throughout the withdrawal process and to make sure you feel supported before and after you leave the hospital.

How do I use this book?

We suggest you read this guide from the beginning. This guide has three parts:

- **Section 1:** What to Expect Before You Deliver
- **Section 2:** Care for Your Baby in the Hospital
- **Section 3:** Transition to Home

You’ll find this additional information in the back of the book:

- **NOWS Symptom Tips:** A list of symptoms with some suggestions that may help.
- **Resources:** A list of helpful resources.
- **Glossary:** Words you may hear in the hospital.



Section 1

What to Expect Before You Deliver

The days and weeks before the birth of your baby can be very exciting and stressful. Many people have a fear of the unknown. We hope this guide will help answer many of your questions and leave you feeling prepared. All questions are encouraged, so write them down and ask your care providers those and any other questions you may have.

We understand you may feel emotional right now. The goal is a healthy delivery and a safe start for you and your newborn.

I seem to be very emotional. Is this normal?

Being emotional is normal as you prepare for the birth of your baby. Here are some things that can help:

- Have a support network that includes friends, family, and trained counselors.
- Contact the hospital where you plan to deliver for tours, classes, and other information.
- Some people find support in spiritual care services. They provide emotional support and spiritual care according to your needs and preferences. If you would like spiritual support during your stay, please ask your nurse to contact them.
- There are many resources available to help you, including your primary care physician and obstetric provider. If you are using substances, including alcohol, please get help right away by calling your obstetric provider or 211.
- Other resources are also listed on page 28.

What is NOWS?

Your baby may have symptoms of withdrawal, which we call Neonatal Opioid Withdrawal Syndrome (NOWS). Your baby is at risk of NOWS if they were exposed to certain substances while you were pregnant. Some of these substances include:

- | | |
|------------------------|---|
| • Heroin | • Hydrocodone (Vicodin) |
| • Morphine | • Meperidine (Demerol) |
| • Codeine | • Fentanyl |
| • Oxycodone | • Methadone or Buprenorphine (Suboxone/Subutex) |
| • Oxycontin (Percocet) | |

How can I help?

- **Answer questions honestly** — All pregnant patients are asked questions by their healthcare providers to help them have a healthy baby. Be honest with the people who take care of you and your baby. Tell them about your symptoms and cravings.
- **Follow the plan** that you and your provider agree upon.
- **Keep taking the medicines that have been prescribed** for you by your health care provider. They may have been prescribed to you for conditions like depression, anxiety, or substance dependence. Even though these medicines can cause NOWS in your newborn baby, it is much worse for you and your baby if you are not treated. Your baby needs a healthy birth parent..

Will my baby be born with NOWS?

It is hard to tell whether a baby will be affected before they are born. Nurses and doctors will watch to see if your baby has signs of NOWS after they are born.

How soon will we see signs of NOWS?

Most babies who have NOWS will show signs 2 to 3 days after they are born. Some babies do not show signs until 7 days after. This depends on:

- What substances they were exposed to. Tobacco, caffeine and some medicines may cause symptoms in the first day. Symptoms of opiate withdrawal usually start around 48 hours of life.
- When they were exposed, especially if it was in the days just before birth.
- Your baby’s gestational age (how long your pregnancy was).

What are the symptoms of NOWS?

Symptoms of NOWS include:

- | | |
|---|--|
| • High-pitched cry | • Trouble sleeping |
| • Tremors or jitters | • Tight muscles (arms & legs seem stiff) |
| • Difficulty feeding and sucking | • Skin irritation |
| • Poor weight gain | • Big response to being startled (called hyperactive reflexes) |
| • Fast breathing rate | |
| • Irritability or fussiness and trouble being comforted | |

What do the doctors look for to be certain my baby has NOWS?

They may be diagnosed with NOWS if they have some or several of the symptoms listed above. These may also be seen in babies who have other problems, so your baby will be closely observed.

How long can the signs and symptoms of NOWS last?

It is hard to say how long the symptoms will last. Rarely, they can last up to 9 months. Once at home, your baby may cry more than other babies or have trouble sleeping for several weeks or months.

The symptoms will slowly get better and we will teach you how to care for your baby at home before you leave the hospital.





Section 2

Care for Your Baby in the Hospital

How long will my baby need to be in the hospital?

Your baby's doctor will decide how long your baby needs to stay in the hospital. Most babies need to stay in the hospital for at least 5 to 7 days for monitoring. If your baby needs medicine, they may need to stay in the hospital for longer.

Does my baby need any special care?

If your baby is born healthy, your baby will stay with you in your room (this is called rooming-in). Your loving care is the best treatment for NOWS. We will have you care for your baby as much as possible in the hospital.

We will care for you and your baby in the same way we care for any other birth parent and baby. Please look at your hospital's guide for information on the basic care of yourself and your newborn.

Will my baby be tested for substances?

Most babies who are at risk for NOWS will have their urine and first bowel movements (called meconium) sent to the lab for testing. We also may use a small sample of the umbilical cord for testing.

Other things to expect

While you are in the hospital, someone from the social work department, case management, or nursing will come and talk to you to help in the transition to home. They will talk to you about a Plan of Safe Care for your baby.

- We will notify the State of Maine so that you and your baby can get the support services that you need. This is required by law. Please note that these services are here to help you and your baby, not to take your baby away.
- If you are from New Hampshire, please talk to the hospital social worker about your Plan of Safe Care and any support that you may need.
- We also refer your baby to Child Development Services. Child Development Services come to your home and help you with questions about your baby's development.

Feeding and weight gain

How will my baby's weight be different from a baby who has not been exposed to substances?

It is common for newborns to lose some of their birthweight (about 6-8%) after they are born. We expect these babies to be back to their birth weight in two weeks. Babies with NOWS may lose more weight and have a hard time putting the weight back on.

- We will watch to see how your baby is feeding.
- You will be asked to record feedings in a Newborn Care Diary.
- We will weigh your baby daily.

Why do babies with NOWS have a hard time putting weight back on?

Babies with NOWS are very active and use a lot of energy. Some babies with NOWS may have a hard time feeding.

- Some babies with NOWS need to be on special formulas with higher calories. This can be added to your breastmilk feedings.
- If you are breastfeeding, ask for a lactation consultant to help you.

Can I breastfeed my baby?

In most cases, we encourage you to breastfeed your baby. If you have any questions about medicines you are taking, please ask your nurse or doctor or lactation consultant.

- If you are using marijuana, your breast milk is not safe for your baby. Please do not use marijuana during your pregnancy or during breastfeeding.

Do I need to watch out for anything when doing diaper changes?

Babies who are withdrawing can have diarrhea. Babies with NOWS are also more likely to get diaper rash and may need special cream.

- Change your baby's diaper often when they are awake. This will help keep your baby's bottom clean and dry.
- Please let the nurse know if you see redness on your baby's bottom.

Eat Sleep Console (ESC) Assessment

We will use the Eat Sleep Console (ESC) Assessment to check for signs of withdrawal.

- This helps us see if your baby’s symptoms are affecting how they are able to feed, sleep, or be consoled (comforted).
- We use this tool to help decide how to best care for your baby.

How will my baby be checked for signs of withdrawal?

You and your baby’s nurses will work together to check for signs of withdrawal.

- The nurses taking care of your baby will use the ESC Assessment to check your baby every 3 to 4 hours, after your baby has eaten.
- You will be asked to record information about your baby in the Newborn Care Diary. We want to know:
 - » How well your baby is feeding.
 - » If your baby is able to sleep for at least one hour before waking after feeding.
 - » How easy or hard it is to soothe your baby.

Medicines for your baby

Some babies will need medicine so that they can feed, sleep and interact with you.

How much medicine will my baby be given?

If your baby does need medicine, the dose and how often it will be given will depend on:

- Your baby’s ESC assessment.
- Your baby’s weight.
- How well your baby is sleeping.
- Your baby’s response to comforting.

How will the doctors know my baby is getting enough medicine?

We will do the ESC assessment to see if the medicine is helping or if they need more.

Providing supportive care for your baby

Can I spend time with my baby?

Yes, your loving care is the best medicine for your baby and we want you to spend as much time with your baby as possible. We will help you learn about your baby and how to care for them.

Here are some ways you can help care for your baby:

- **Room in together:** One of the best things you can do for your baby is to keep them with you at all times in your own room. Being close to your baby helps you get to know them and learn how to respond to their needs. Your baby will feel safest and most comfortable when close to you.
- **Skin to skin:** Spend as much time “skin to skin” as possible with your baby when you are awake. This means holding your baby with their skin touching your skin, usually against your chest. This helps your baby eat and sleep better, and will help calm your baby. It can also help your milk supply when breast-feeding.
- **Swaddle:** Swaddle your baby in a light blanket. Being in a swaddle helps your baby feel safe and comfortable.
- **Keep a calm room:** Keep your room quiet with the lights dim. Loud noises (like TV, music, and voices) and bright lights may upset your baby.
- **Let your baby sleep:** While in the hospital, ask your nurse to do their check-in during feeding times so that your baby does not need to be woken up.
- **Know their hunger cues:** Feed your baby whenever they are hungry until they are content. Some babies want to eat as often as every 1 1/2 to 2 1/2 hours.
- **Sucking:** If your baby still wants to suck after a full feeding, offer a clean finger or pacifier to suck on. This can be very comforting for your baby. Always make sure your baby is not hungry first.
- **Limit visitors:** Try to have only 1 or 2 visitors in your room at a time to help keep the room quiet. The more visitors there are, the noisier your room will be and this may make your baby fussy or not sleep as well.

Where should my baby sleep?

Anytime your baby is put to sleep, it is always safest to place them on their back.

- Babies should sleep on a flat mattress in their crib.
- Do not put anything in your baby’s crib, such as stuffed animals or loose blankets.
- They should sleep near their parents or caregivers, but NOT in the bed, couch, or chair with other people or children.

Remember, if you are sleepy put your baby down in a crib or bassinet.

A good way to remember Safe Sleep is “ABC”.

It is always safest to place your baby on their **Back** to sleep. Babies should sleep **Alone** in a **Crib** near their parents but should not sleep in the bed, couch, or chair with their parents.

For more info on Safe Sleep, visit safesleepforME.org and Safe to Sleep NICHD.





Section 3

Transition to Home

Babies with NOWS need a good routine and a lot of rest. You are probably already learning about what your baby likes. Try to plan your activities around your baby’s schedule. Well-rested babies eat better and are usually happy, alert and ready to learn about their world.

Will my baby still have symptoms of withdrawal once they are home?

Most infants have an amazing ability to recover from early problems. This includes babies with NOWS.

- Once at home, your baby may have mild signs of withdrawal like crying or difficulty sleeping for several weeks or months. The symptoms get better over time.

Is my baby fussy because of NOWS?

There are many things that all newborns have in common, such as a fussy time. Most babies have a fussy time in the evening.

- The soothing techniques you learned in the hospital may help at home too along with the information provided from the “Period of PURPLE Crying” web app that you will receive prior to discharge from the hospital.

Feeding at home

Is there anything special I should do when feeding my baby?

Feeding your baby may be harder than you expected. Ask the nurses and lactation counselors about infant feeding cues which will help you learn when your baby is hungry.

- It is important for both you and your baby to be comfortable while feeding:
 - » Always hold your baby while they are eating.
 - » Some babies like to be swaddled or held closely while feeding. Others like their arms free.
 - » Some babies like to be fed leaning back slightly. Others like to be held upright.
 - » Your baby will let you know what they like best.

Is it normal for my baby to have trouble feeding?

Feeding may be difficult in the beginning. Your nurses and lactation consultants will help you learn about your baby’s feeding needs during your hospital stay.

- Your baby may suck on their hands, munch, increase movements, and cry. It may or may not mean that your baby wants to eat.
- Your baby may show signs of being full or tired even when they have not had a full feeding. Before stopping a feeding, try to burp your baby or gently encourage them to finish the feeding.

How often should my baby eat?

Your baby’s care team may recommend a different feeding plan, but in general, once they are above their birth weight and gaining weight well:

- Breastfeeding: A feeding every 1 ½ to 3 hours, aiming for 8 to 12 feedings every 24 hours.
- Bottle feeding: They should eat about every 2 ½ to 4 hours.

Babies will take more at some feedings than at others. Keep track of your baby’s feeding with the Newborn Care Diary.

- If your baby seems to spit up often, try smaller feedings, but feed more often.
- As your baby grows, he or she will take larger feedings, but may feed less often.

Your baby may have trouble eating enough to gain weight.

- Providing high calorie formula or adding calories to breastmilk may be needed for some babies.

Sleeping at home

How long should my baby sleep?

Most babies with NOWS will go home from the hospital when they are 1 to 3 weeks old. At this age, infants usually sleep 16 to 20 hours a day.

Falling asleep and staying asleep are important things for your baby to learn how to do.

- Using consistent naptime and bedtime routines before sleep can help your baby fall asleep easier.
- It may take 6 to 9 months for babies with NOWS to develop a good sleep routine.

How can I help my baby sleep better?

- While in the hospital, ask your nurse to do their check-in during feeding times so that your baby does not need to be woken up.
- Keep the lights low in the room where your baby sleeps.
- Give your baby a pacifier for soothing while falling asleep.
- Help your baby learn that night is for sleeping, not playing. Keep nighttime feedings boring and quiet.
- Use a bedtime and naptime routine that is calm and quiet.
- Play soft music for about 20 minutes to soothe your baby and help them fall asleep. Use a CD or phone speaker, instead of a wind-up toy.

What are other ways I can keep my baby safe while sleeping?

- Don't let your baby get too hot. Babies usually only need one more layer than you have on.
- Do not put fluffy blankets, toys or stuffed animals in your baby's crib while they sleep.
- Don't put the crib near window shades with cords or bookshelves with books, televisions or other heavy items.
- Many babies like swings and vibrating seats, but some babies with NOWS may find them too stimulating. These are not safe for sleep.

Awake time

What should I do when my baby is awake?

Sometimes between naps, your baby will cry. Other times your baby will be awake and alert and this is a time when you can interact and play with your baby.

- Change your baby's position often during the day so they can learn about their world and develop their muscle. Try holding your baby facing toward you or facing out, on your shoulder or on your hip, or secured in a swing or seat.
- Spend 10 to 20 minutes each day doing "tummy time." Put your baby on their tummy on a firm surface (a blanket on the floor is best) while you are watching. This will strengthen the back and shoulder muscles and your baby will learn to move around. Remember, your baby should always sleep on their back, not on their tummy.
- Cuddle up with a book or a song. Hearing your voice or soft music can be soothing, especially when your baby is restless or tired.

How should I touch my baby?

Babies with NOWS can be very sensitive to touch. However, touch is one of the ways all babies learn and become more aware of their bodies.

Gentle, slow massage is a soothing way to interact with your baby and to give loving care. If you make time for massage as part of your regular routine, such as after bath time, your baby will begin to look forward to and enjoy this activity.

Crying

Crying is your baby's way of talking to you. Some babies cry more than others.

What should I check when my baby cries?

- Check the diaper to see if it needs to be changed.
- See if your baby needs another burp or is hungry.
- Try swaddling your baby in a blanket so they feel more secure.

- Look around for things that could be bothering your baby.
 - » Are they too warm or cool?
 - » Are there sights and sounds from the television or music too stimulating rather than soothing?
 - » Is light shining in your baby's eyes?
 - » Has your baby been in the same position for a long time?
 - » Has it been a busy day, and your baby needs to go to sleep?

What if I can't stop my baby from crying?

If your baby seems to be crying a lot, please call your baby's health care provider. This could be a sign that something is wrong. Your health care provider may be able to suggest some other helpful techniques or resources.

Do not let yourself get too upset by the crying before you ask for help. Remember to never shake a baby.

The Period of PURPLE Crying:

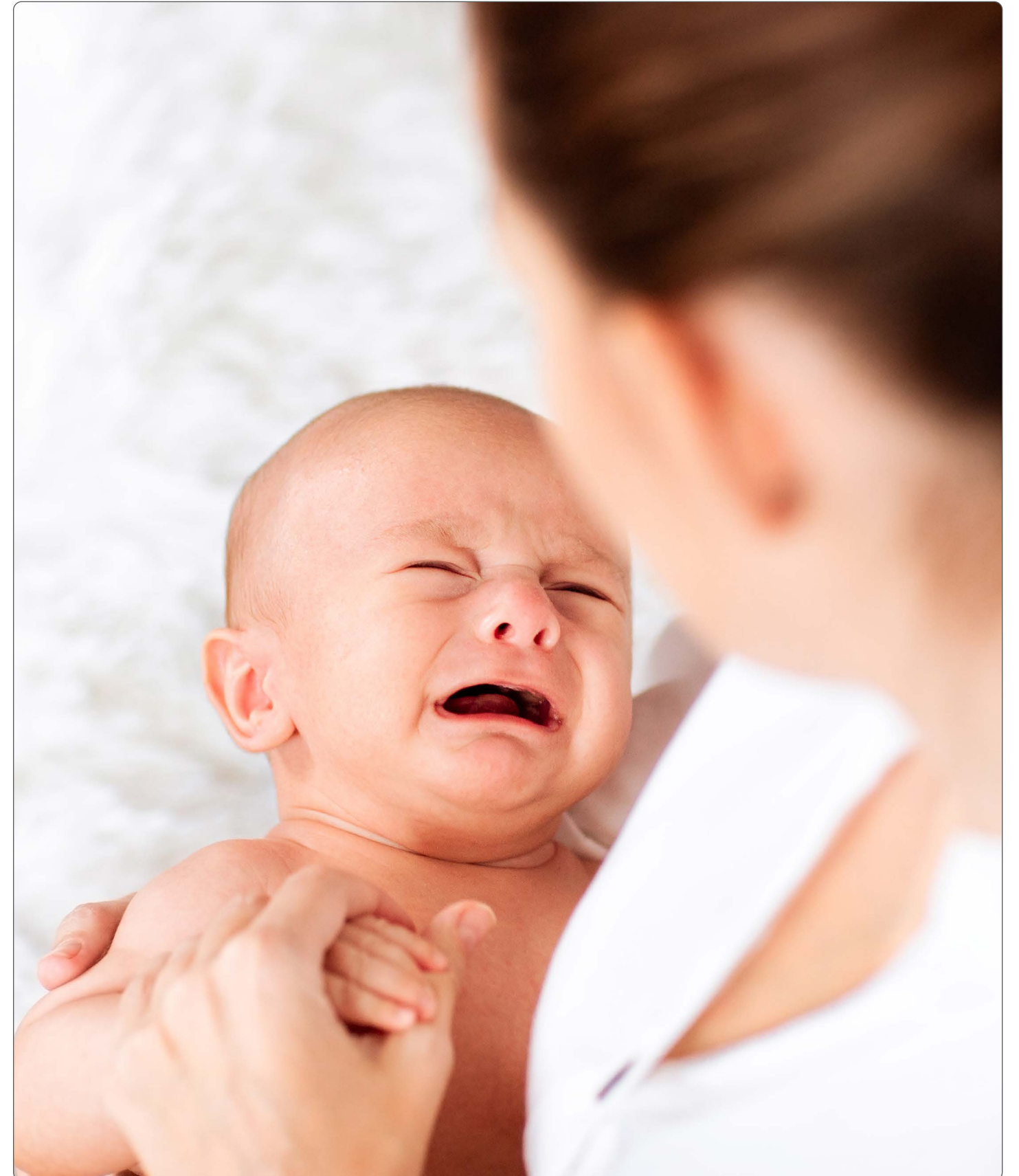
The "Period of PURPLE Crying" begins at about 2 weeks of age and continues until about 3 to 4 months. All babies go through this period, or phase. It is a normal part of every infant's development. During this time some babies cry a lot, while others may cry less. Some people refer to this period as "colic" and it is not a disease or illness.

You will receive a Period of PURPLE Crying web application code when you leave the hospital.

- You can also visit this website for more information: purplecrying.info
- The Period of PURPLE Crying website includes more information about this period and soothing techniques to try.

PURPLE stands for:

- **P**eak of crying
- **U**nexpected
- **R**esists soothing
- **P**ain-like face
- **L**ong-lasting
- **E**vening



NOWS symptoms and tips

Refer to this chart for ways that you can help your baby with some of the symptoms of NOWS.

Symptom	Tips
Difficult or poor feeding	<ul style="list-style-type: none">• Your baby may need more time to feed than others.• Feed your baby with the same nipple type as was used in the hospital.• Feed small amounts more often. You may need to use a special formula to make sure the baby is taking in enough calories.• Feed in a quiet, calm place with little noise and interruptions.• Swaddle your baby to keep their arms and hands close to their body and reduce extra movement.• Be alert to your baby’s cues. They may include searching or pulling away from nipple or needing to pause to swallow or burp.
Sneezing, stuffy nose	<ul style="list-style-type: none">• Call your pediatrician, especially if your baby is working hard to breathe.• Keep your baby’s nose and mouth clean.• Do not overdress or wrap your baby too tight.• Keep your baby in a position where the head is above the heart, well supported and supervised.• Do not let your baby sleep on their tummy.• Ask your baby’s doctor about saline drops.

Symptom	Tips
Spitting up	<ul style="list-style-type: none">• Feed your baby slowly. Let your baby rest between feeds.• Feed your baby less but more often.• Burp your baby often.• After feeding, keep your baby upright in your arms for 20 minutes to help with digestion.
Trembling or shaking	<ul style="list-style-type: none">• Keep your baby in a warm and quiet room.• Swaddle your baby snugly.• When positioning your baby, move slowly and carefully to not startle them.• Gently and slowly, massage your baby’s arms and legs.

Resources

We are here to support you and there are a lot of resources available to help you and your baby. These resources include help with finding:

- Substance use treatment
- Recovery support
- Food, housing, and transportation.
- Programs that help new parents.

To see a list of these resources, please scan the QR code below by opening the camera on your phone and clicking on the link that pops up.



Or go to this link: mainehealth.org/pregnancysud

Glossary

Words you may hear in the hospital

Department of Health and Human Services: a system that provides resources and services that are important to keeping people healthy. This system allows for easier access to services and care is coordinated between the services.

Eat Sleep Console Assessment: a way for your baby’s healthcare team to measure their withdrawal symptoms and then create a plan of care for your baby.

Gestational Age: the age of the baby in weeks, starting from the beginning of the pregnancy to the date of birth.

Meconium: the first stool (poop) passed by the baby. It is often black and sticky.

Neonatologist: a pediatrician trained in caring for high-risk newborns.

Public Health Nurse (PHN): nurses who can check on you and your baby to keep you both healthy at home. They can check to see how feeding is going and can check your baby’s weight.

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