

Welcoming a Baby With Down Syndrome

(The cheat sheet we wish we'd gotten.)

First things first—congratulations!

You just welcomed your sweet baby into the world. Honestly, that's where this cheat sheet should end.

But we get it. Your heart is full, your mind is racing, and you probably have a million questions.

You're going to get plenty of medical information and advice. So we won't bombard you with another checklist. **These are just a few things we think every new parent of a baby with Down syndrome deserves to hear.**

1. Start With This

- ☐ **Your baby is more alike than different.** They'll eat, sleep, cry, and want to be held just like any other baby.
- ☐ **Enjoy the newborn stuff.** Take photos. Breathe in that newborn smell. Enjoy the soft cheeks and sleepy stretches. Don't rush past the magic of this stage.
- ☐ **You don't have to know everything about Down syndrome today.** You just became a parent. That's enough.
- ☐ **Trust your gut.** You already know your baby best.

2. Health Stuff (Just the Basics)

Your baby will likely have some extra screenings and appointments—heart, hearing, thyroid, vision, and more.

- ☐ **Ask your pediatrician to help coordinate referrals.** There's a good chance they'll do this without you even asking.
- ☐ **Prepare for long appointments (and even longer waits).** Bring extra baby toys, more diapers than you think you'll need—and plenty of snacks for yourself.
- ☐ **Keep a small folder or note on your phone for medical info, just to stay organized.** It can quickly pile up, and memorizing can be draining.

☐ **PLEASE. STEP AWAY FROM GOOGLE.**

It'll just give you a hundred new things to worry about and send you into a spiral for no good reason. **“Higher risk” for various health conditions does not mean “likely.”** If you have concerns, talk to your pediatrician about what actually applies to your baby.

If your baby needs heart surgery, take a deep breath.

It's a lot. This is one of those times when love feels heavier than you thought it could. You'll have questions, decisions, and probably some very long days. **Lean on your baby's care team, ask every question you need to, and don't feel like you have to be brave every minute of it.**

3. Early Support (When You're Ready)

Every state has an Early Intervention (EI) program—free* therapy (like physical, occupational, and speech) for babies with developmental delays or disabilities, ages 0–3 years.

- ☐ **Get Early Intervention on your radar.** Ask your pediatrician for a referral or contact your state's program directly. Just search “[your state] Early Intervention program.”
- ☐ **Ask what services are available and what they cost.** Evaluations are free, and many services are provided at no cost. Some states use a sliding-scale fee system, but families cannot be denied services because they're unable to pay.

And no, this doesn't mean your newborn needs a packed therapy calendar.

It just means you're getting the process started. You're not “behind” if your baby isn't in therapy yet.

*A few states have a family cost participation system (a small sliding-scale fee based on income). But by law, no one can be turned away because they can't pay.

4. Your Everyday Life

- ☐ **Treat your baby like...your baby.** Read, sing, snuggle, laugh. All the regular baby stuff.
- ☐ **Remember that milestones aren't a race.** Your child will learn and grow on their own timeline. **Celebrate the progress, not the calendar.**
- ☐ **Down the road, your child will have many wonderful opportunities.** Organizations like Special Olympics and Best Buddies International are working for inclusion every day so you can just enjoy this baby stage.

A reminder:

You don't have to plan for kindergarten or adulthood right now. The only “schedule” that matters is nap and cuddle time.

5. Family, Friends, & (Too Much) Advice

- ☐ **Expect some awkward comments.** People mean well, but even the most loving friends will probably say the wrong thing at some point. Take what helps, and try to let the rest go.
- ☐ **Prepare for the flood of articles and inspirational videos.** Everyone and their mother may suddenly have a story about a child with Down syndrome. Many will be sweet—but they might very well feel overwhelming right now. You don't have to read or watch everything now—or ever. It's perfectly okay to say:

Thanks for sending. I'm setting this aside for later. Right now, I'm just focusing on my baby.

6. All the Feelings? Totally Normal.

You might feel joy, fear, anger, love, sadness. Sometimes all before breakfast. Feel whatever you're feeling—sans guilt.

Here's something many parents who've been in your shoes would love to tell their younger selves:

There's so much love and joy ahead that you can't even imagine yet.

Trust us—it will come.

Bottom line: Your baby is here—and they're perfect. ♥

You don't have to know everything, fix everything, or plan everything. Just love them, hold them, and let life unfold one day at a time.

Bonus: What to Say When Someone You Love Has a Baby With Down Syndrome

The only right answer is

“Congratulations! They're beautiful.”

Save yourself some Googling.

More Caregiver Cheat Sheets at [WeCareOutLoud.org](https://www.wecareoutloud.org)