



# get through your child's hospital stay

The essential guide we hope you'll never need, straight from a mom who's been there—for 123 days. by VIRGINIA SOLE-SMITH

**IN THE FIRST** three years of her life, my daughter, Violet, spent more than six months living in the hospital. During that time, she underwent three open-heart surgeries and nine other operations, many of which were performed under emergency circumstances in order to save her life. She also faced hundreds of blood draws, X-rays, and other minor procedures, none of which feel minor when they're happening to your kid.

Violet is our only child, so my husband, Dan, and I had to learn how to be parents under the harsh fluorescent lights of the pediatric ICU, where every day could bring the best or worst news imaginable, and every beep of a monitor reminded us of our deepest fears.

Violet's story is complicated and frightening, though we expect it to have a happy ending; today she is a resilient and cheerful preschooler.

Her condition (a severe form of congenital heart disease) is, thankfully, rare. But her status as a hospital "frequent flyer" is unfortunately not as unusual as you might think. In fact, Violet is just one of more than 2 million non-newborn children who are admitted to American hospitals each year. Roughly 25 percent of these pediatric patients are under the age of 1, and most are there because of



Your soothing touch releases oxytocin and serotonin, so her medical tests are less painful.

infections such as pneumonia or bronchitis or for congenital health issues. And while the average visit is just over five days, 10 percent of children ages 1 to 17 end up being readmitted, found the Agency for Healthcare Research and Quality.

The good news is that thanks to big leaps in research and training, most hospitals are saving more lives and providing better care than ever before. They are doing so, in part, because of a crucial shift in the medical mind-set that has allowed parents to play a bigger role in their child's care. Today parents are encouraged or even expected to sleep over in their child's hospital room, and to learn how to administer medications or run medical equipment in preparation for discharge. "When parents get more involved, we know the odds of their child doing well at home will increase," says Tricia Hiller, director of the Child Life and Creative Arts Therapy Department at Maria Fareri Children's Hospital, in Valhalla, New York (where Violet receives her care). But with

these new responsibilities comes, well, more responsibility. This is how to be the best possible advocate for your child.

**1 Be there.** Every expert who was interviewed for this story agreed that this is a crucial way parents can improve their child's medical care. "Be physically present at the hospital as often as your job and your other family responsibilities allow," says Mark Schuster, M.D., Ph.D., chief of general pediatrics at Boston Children's Hospital. If your time is limited, talk with your child's care team about when your presence is most important: It may be overnight when your child is in the most pain or in the morning when the doctors make rounds. Figure out what works best, then develop a plan with family or friends who can act as your proxy when you're unavailable. Keep in mind that your child's attending physician probably only comes in at select times each day. If you can't be there then, ask when you can call in for an update. "Make it clear to the doctor that you will

fully participate in all decision-making," advises Dr. Schuster.

This doesn't mean you shouldn't take breaks. In fact, the opposite is true. "Even if it's only ten minutes, be kind to yourself," says April Perri, of Newburgh, New York, whose daughter was hospitalized for 140 days last year. "When you're in for the long haul, it's essential to take care of yourself or you won't be able to keep on going."

**2 Offer your expertise.** It's easy to feel intimidated when you're surrounded by doctors and specialists. So remind yourself: "I am the expert on my child," recommends Dr. Schuster. You know your child's "normal" better than the medical team when it comes to appetite, energy level, sleep habits, and so much more. Parents of newborns, in particular, may struggle with this, but I found myself surprised by how much I already knew.

**3 Ask questions.** Except in circumstances when a doctor has only minutes to save a life, she should be willing to answer your questions. If she uses medical jargon you don't understand, ask her to translate or to give you some literature to read, then set a time for a follow-up conversation. Keep a notepad handy so you can jot down questions whenever they come up throughout the day and night.

**4 If you see something, say something.** "If a medication doesn't look right, ask to double-check it. If a medical test isn't what you were told to expect, speak up," encourages Amy Kratchman, who works as a family consultant to improve family-centered care at The Children's Hospital of Philadelphia. "It's always better to confirm any detail that doesn't seem right." This applies to cleanliness as well: Over the course of Violet's multiple



## ➔ A Notebook Is a Necessity

It's the hospital's job to track every test, meal, and medication your child receives—but mix-ups happen, so keep your own log. Turn a notebook with file pockets into a central place to keep questions, paperwork, and all key information on your child. Include names and dosages of medications, contact info for all doctors, and your insurance card plus a photocopy.

Log the dose, day, time, and name of the staffer who administered each medication. (When you're on a break, ask a friend to take over.) Note what your child's eating, how much, and how often. If you'll be giving medicine or following a prescription diet at home, keep the log going and make sure all caregivers know how to use it.

hospital stays, she picked up two upper-respiratory viruses as well as a bacterial infection in one of her chest tubes that quickly turned septic and required emergency surgery to fix. You can't prevent every possible infection (and you'd go crazy trying), but you can help to make sure that every single person washes his hands before he touches your child (or uses any medical equipment). You might feel awkward asking hospital staff to wash their hands again "so that you can see them do it," but consider this the time where it really is okay to be that parent. Feel free to preface your request with "I'm sorry, but I'm a germaphobe..."

## 5 Plan for the whole family.

If you have other children at home, you already know that a

single child's hospitalization will impact everyone in your household. Try to keep your other kids' routines as normal as possible. See whether grandparents or family friends can help out with drop-offs, pickups, and after-school activities. "Give your other children's teachers a heads-up about the situation," says Hiller. "They'll need to be prepared for outbursts or missed homework and other challenges." Keep siblings connected by arranging for some family dinners or after-school visits at the hospital if their schedule and your sick child's condition allow. If he needs to be kept in isolation, schedule a daily video-chat so that everyone can catch up. None of this will be easy, so try to remember that the situation is temporary.

When Jennifer Marquez's newborn, Louisa, spent 12 days in the NICU, her older daughter, Vivien, struggled with her mom's absence. "They don't allow 3-year-olds in the NICU, so she kept asking where her new baby sister was, over and over again. And she wanted 'Mommy' constantly, which was difficult because I was making a one-hour trip each way to the NICU every day," says Marquez. "I essentially felt guilty all the time until we got to take Louisa home."

**6 Continue parenting as usual.** "Consistency is key because it makes your child feel safe," explains Hiller. "If she has to say 'please' and 'thank you' at home, she should do that in the hospital. If you throw out all the rules, that conveys something is really wrong, despite the fact that you're telling her she'll be okay." Try to preserve a few familiar elements, such as reading her favorite bedtime story. And cuddle, feed, bathe, and change diapers to whatever extent you can, even if the nurses need to teach you how to do it around tubes and wires.



## More Tips From Parents Who've Been There

**"Bring hand lotion. The nonstop sanitizing really dries out your hands. And when it's time to be discharged, ask if you can take supplies home. We scored lots of extra diapers, syringes—you name it!"**

—Liz Scranton; Centreville, VA  
(111 days in the NICU with preemie twins Chance and Kenzie)

**"Find something to pass the time. I finally knitted Claire that baby blanket I never got around to during my pregnancy."**

—Kelly Carámbula; San Francisco (55 days in the cardiovascular ICU with daughter Claire)

**"Bring headphones. The persistent beeping and other background hospital noises can be relentless. Listening to good music, podcasts, or audio books was a huge help in tuning out the crazy."**

—Jennifer Marquez; Atlanta (10 days in the NICU with premature daughter Louisa)

**"Our room only had a 'recliner' for parents to sleep in—which barely reclined. After one night of that, I brought in a twin-size air mattress. Lifesaver."**

—Kate Carpenter; Pelham, NY (13 days in the PICU with newborn daughter Casey)

**7 Assert yourself.** A lot of what happens in the hospital is nonnegotiable, because your child needs that IV, blood draw, or test to make him better. But many situations leave space for negotiation. If your child hates having her temperature taken in her rectum, ask if it would be appropriate to use a different thermometer, such as one that slips under her armpit or possibly into her ear. When it came to needles, we always requested the staff person who is most comfortable drawing blood from babies (hint: It's often a NICU nurse who may need to be paged). For us, it worked to set a one-stick limit; if the nurse (or tech) couldn't draw blood or place an IV on the first try, we took a break and started again later with a new technician.

There are times when it's okay to flat out say no. We've turned away well-meaning housekeeping and janitorial staff when they arrived to mop floors or empty the trash cans during naptime (a "He's sleeping!" sign on the door does the job nicely). When possible, try to give your child opportunities to exert some control over his schedule. "We always respect when a child says he doesn't want to play with us," says Hiller, who often stops by patients' rooms with toys and other activities. "It's pretty much the only decision he gets to make here, so we want to honor that." Perri went into her daughter's first hospital stay thinking the doctors always knew best. "I didn't realize you can actually say no to stuff. And I'm a people pleaser, so that was hard to learn. But I realized it's about standing up for your child," she says. "When you push back and make something easier for your child, no matter how small, it feels so good."

**8 Go over the home-care plan in detail before being discharged.** Leaving the hospital may be the most terrifying part of the entire stay—because now

you need to work without a safety net. Make sure you know what medications to give, how much, and how often. If the schedule seems unsustainable, ask your doctor how you can tweak doses so you aren't waking your child up at 3 A.M. or giving medicine all day long. It's also smart to ask your doctor to call prescriptions in directly to your pharmacy. This is a time-saver and ensures that the pharmacy will be able to fill prescriptions for more unusual medications. Don't forget to check in with your child's social worker or case manager too. He can help you navigate insurance and other financial hurdles, and also pinpoint support groups, therapists, and other resources your family may benefit from after you leave.

**9 Ask for a list of red flags.** You're going to worry about everything (especially on that first night home). Have your doctor talk through what's normal and which signs and symptoms are truly a cause for alarm. Many of Violet's doctors are available to us via text or e-mail now, which gives us tremendous peace of mind. If your child's condition is fragile, don't be afraid to ask about those options.

**10 Be honest about your feelings.** If your child will require any kind of medical equipment once you go home, tell the staff what kind of training and preparation you'll need to feel ready for that. "We took our daughter home on a feeding tube and thank goodness I said, 'I'm petrified' before we left," recalls Kratchman, whose daughter was born with a mitochondrial disease. "That let the nurses know I needed more practice and reassurance. You don't have to be brave." The fact is, life may look very different for your family for some time now. Don't leave until you feel ready to care for your child at home.

## ➔ How to Help a Friend

An overwhelmed parent often doesn't know how to ask for support. Here's what you can do.

\* **Send healthy food.** Many well-wishers come with treats, but your friend more likely wants a salad for lunch or an easy-to-microwave dinner. Ignore this tip if your friend mentions craving junk food. If you'd like to bring food for your friend's child, ask if that's permitted.

\* **Give a gift card.** Restaurant gift cards help with the food bill, iTunes or Amazon let your friend load up on entertainment, and a good old Visa gift card can go toward bills and incidentals.

\* **Stop by with a cell-phone charger.** Odds are, she could use a spare. Other practical gifts: deodorant, extension cords, cleansing wipes, and breath mints. Disposable plates and cups are handy too.

\* **Visit on a weekday.** Visitors pile up on weekends, which can be stressful to manage. If you can spare two hours, come midweek instead. Call first.

\* **Remember the diagnosis.** If it's obscure, take the time to read up on it a bit on your own.

\* **Volunteer to pet-sit, water plants, and collect mail.** Ask who's coordinating such things and call directly to offer.

\* **Clean her house.** Hire a service if you don't live locally.

\* **Stay away if you're sick.** Or if anyone in your home is sick. Or if you haven't gotten a flu shot.

\* **Say "However long this takes, I'm here with you."** Remember: Time is standing still for your friend, and recovery can be maddeningly slow.

**DARE TO CARE**