

ABSOLUTE BEGINNERS Crib Sheet



Photo by Nicole Tavenner

When Your Baby Is Diagnosed With Down Syndrome

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TAKE TIME TO GRIEVE THE LOSS OF THE BABY YOU WERE EXPECTING

Few of us dream of having a baby with special needs—odds are that the diagnosis was unexpected. With it comes the loss of whatever you'd already begun imagining for your family, whoever you thought your baby might be. Let yourself feel this loss. By allowing time and space to process these feelings, you will make way for the new feelings that will come for your baby.

TALK ABOUT IT

Tell people about the diagnosis, and why it makes you sad (if it does), and why you are scared (if you are). Family members and well-meaning friends will look to you to set the tone of the experience, and sometimes this can be difficult to manage. It's OK to say, "It's hard for me to talk about, right now," if that's how you're feeling. And it's also OK to not have all the answers, right away. You will find them, in time, as you and your family get to know your baby.

MEET A BABY WITH DOWN SYNDROME

Many of us have never had the chance to know a baby or a young child with Down syndrome. Once you do, you will see that there is no mystery here: Babies with Down syndrome need all the same things as other babies—snuggling, holding, play, care, protection, and most of all, love.

THE DIAGNOSIS OF DOWN SYNDROME WILL TELL YOU THINGS ABOUT YOUR BABY, BUT NOT EVERYTHING

Down syndrome is a genetic condition that affects the 21st chromosome pair—but there are many more chromosomes at play in building a human being. Will your baby have your smile? Daddy's hair? These things are unique to your family and will be a part of your baby. My son Avery has his father's distinctive big toe, and in the beginning, when I was a new mom to Avery, I used to wrap my fingers around it, as a way of feeling connected to him.

ENROLL YOUR BABY IN EARLY INTERVENTION

To help your baby get the best start in life, meet with a speech therapist, a physical therapist, and an occupational therapist. A speech therapist can help even the youngest babies develop the breathing patterns and muscles used first for feeding, and later for speech. Physical therapy will help your baby develop a strong muscle core, which is important for all physical activity, especially walking. And occupational therapy builds your baby's ability to process information she gets through the senses. Good therapy looks and feels like play, and is a wonderful way to get to know your baby.

FIND THE RIGHT DOCTOR

Many doctors "get" babies with Down syndrome, but some don't. You have a right to doctors who are delighted to care for your child, who understand Down syndrome, and who support your role as a proactive and caring parent. If you don't have such a team in place, find it!

KNOW THAT YOU HAVE SUPPORT

Down syndrome is part of 350,000 families and is present in all walks of life in every culture. Loving a baby with Down syndrome is a special experience, and it's helpful to be a part of a group that understands it—our concerns, our medical issues, our frustrations, and our successes. Fortunately, it's a great time to have a baby with Down syndrome. You can find help online, in person, or in books—whatever is most comfortable for you. Two excellent places to start are the National Down Syndrome Society (www.ndss.org) and the National Association for Down Syndrome (www.nads.org). These organizations provide support, encouragement, publications, research, and advocacy at both national and local levels, and can put you in touch with your greatest resource: other parents who love babies just like yours.

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