

# Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome

*Nancy McCrea Iannone and Stephanie Meredith*



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## Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome

By Nancy McCreannone and Stephanie Hall Meredith

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We have worked for almost a year on this book. The information is based on many hours of research and many discussions with experts. Most importantly, much of the advice is based on over four years of conversations with hundreds of expectant moms waiting for a baby with Down syndrome to be born. We have donated our professional skills and spent a great deal of time trying to give parents the information and support they need for this specific time period, trying to reassure, empower, and educate these parents while understanding and respecting their emotional state. In order to accomplish these goals, our work must remain intact and viewable in its entirety.

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#### Audience

This book is meant to be a resource for parents awaiting the birth of a baby with Down syndrome. The title is *NOT* appropriate for parents making difficult reproductive decisions. Stephanie Hall Meredith has authored a booklet which is appropriate for any patient, including those currently making reproductive decisions, receiving a prenatal diagnosis entitled "Understanding a Down Syndrome Diagnosis." The booklet has also been approved by representatives from the American College of Obstetricians and Gynecologists, the National Society of Genetic Counselors, the American College of Medical Genetics, the National Down Syndrome Society, and the National Down Syndrome Congress. Please refer to [lettercase.org](http://lettercase.org) for more information.

#### A Note to Down Syndrome Groups

As you support parents awaiting the birth of a baby with Down syndrome, we recommend that you provide these expectant parents with a link to [DownSyndromePregnancy.org](http://DownSyndromePregnancy.org), so that they can access the book and its links, and make full use of our interactive blog that supplements the information in the book. If a parent does not have access to the internet, another option is to print the book and provide a paper copy to them. If you do this, it will be helpful if you later provide the parents with access to a computer (at your organization's office, a library, or a member's home) so that the parents can follow the links for more information. We believe that this book is most helpful when viewed online.

## Our Review Team

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**Melissa "Missy" Kline Skavlem**, Down Syndrome Association of Greater Cincinnati Board Member; Board Moderator, Baby Center's Down syndrome pregnancy on-line support board. Mother of Violette, a little girl with Down syndrome.

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## WELCOME

Dear Expectant Parents,

If you are opening the pages of this book, you have probably just received the news that your unborn baby has Down syndrome, and you are moving forward to embark on this journey. After learning about a diagnosis, you often have another four to six months to think about what that diagnosis means for your family. You might be feeling overwhelmed, emotional, confused, and afraid. You may also be feeling very alone and unsure where to turn with all of your questions.

This book was written to help you through this time, to prepare you for the rest of your pregnancy and the newborn stage, and to give you hope for a meaningful future that may be very difficult to picture right now. You are not alone, and there are parents all over the country who are ready and willing to share their experiences, their knowledge, and their support at this time. Many parents are available to provide a helping hand in person, over the phone, or on-line, and this book is a compilation of advice routinely given by professionals and parents of children with Down syndrome.

Your situation is unique and individual, and no one can ever truly understand how you feel. However, we can share what we have learned to help you along your journey.

Our common experience has been that the initial moment of learning the diagnosis is stark and crystal clear, but the days and weeks afterwards are hazy, painful, confusing, and overwhelming. But, after we emerge from that cloud and then live with our babies, we can't imagine our lives any other way. We have developed an appreciation for their unique gifts, talents, and beauty. And now we fiercely love our children, feel a deeper appreciation for humanity and empathy towards others, and realize that life with Down syndrome is hard work but is also remarkably ordinary.

Signed,

Nancy Iannone and Stephanie Meredith

*Please remember that we are parents, not medical professionals. Medical information in this book is provided as a way of organizing information and topics. It is meant to be used as a starting point to encourage useful communication between expectant parents and their medical providers. The information in this book should not be used as a substitute for medical treatment and good quality health care.*

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## EXPLAINING THE DOWN SYNDROME BASICS

Down syndrome is a genetic condition that is usually caused by an extra copy of the twenty-first chromosome. It occurs in approximately one out of every 733 births among all races and income levels.<sup>1</sup> Although 80% of babies with Down syndrome are born to mothers under the age of 35, your chances of having a baby with Down syndrome increase with age.

According to current estimates, about 400,000 Americans have Down syndrome. The medical conditions and abilities of people with Down syndrome can vary widely. However, people with Down syndrome generally have mild to moderate cognitive delays, low muscle tone, and a higher risk for a variety of health issues, particularly heart defects.

Over the past few decades, the outlook for people with Down syndrome has improved significantly thanks to advances in healthcare, education, and public attitudes.

Most medical conditions can be addressed by good health care. As health care research and technology have continued to improve, the life expectancy for people with Down syndrome has almost doubled over a twenty year span. On average, most people with Down syndrome are now living into their 60's.<sup>2</sup>

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- 1 Centers for Disease Control and Prevention. (2006). Improved National Prevalence Estimates for 18 Selected Major Birth Defects --- United States, 1999—2001. *Morbidity and Mortality Weekly*, 54(51&52):1301-1305
  - 2 Yang, Q., Rasmussen, S.A., & Friedman, J.M. (2002). Mortality associated with Down's syndrome in the USA from 1983 to 1997: A population-based study. *Lancet*, 359: 1019-25.

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People with Down syndrome have benefitted from various education programs. For example, Early Intervention services are provided by the states to children before age three. In addition, individual education programs, ranging from inclusion in the typical classroom to small group classrooms, have improved the future for people with Down syndrome. Moreover, there are currently over 250 college programs for people with intellectual disabilities.

Improved public attitudes and acceptance have also meant that people with Down syndrome are thriving as active and valued members of the community. Children with Down syndrome are increasingly joining social and school programs with their peers. Furthermore, many adults with Down syndrome are employed and live independently or with some support.

As you try to grapple with questions about what a Down syndrome diagnosis means for your child, remember that this baby will most importantly be a member of your unique family. Your child will have his or her own individual personality, interests, strengths, and challenges that are partly influenced by that extra chromosome — and also the unique genetics and nurturing in your home.

## USING THIS BOOK

This book gives expectant mothers the essential information they need to know about a pregnancy after learning about a prenatal Down syndrome diagnosis. We have tried to make the information in the book as complete as possible, giving you one resource with the majority of the issues you might face as you await the birth of your child. That said, please know that you will not necessarily encounter every single point that we discuss in this book. Just as your child with Down syndrome will not be exactly like any other child with Down syndrome, your pregnancy will also not be like anyone else's pregnancy. Our goal is to provide you with the tools and information that you will find most useful. If you find any of the information is unduly concerning you, feel free to jump into another section that pertains more specifically to your experience.



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## MONITORING YOUR PREGNANCY POST-DIAGNOSIS

If the results of diagnostic testing reveal that your baby has Down syndrome, you and your health care provider might want to discuss a pregnancy management plan. The pregnancy management plan might include the following:

1. **A fetal echocardiogram.** It is estimated that between 40 to 60% of babies with Down syndrome have some type of heart defect. The vast majority are correctable by cardiac catheterization or surgery, or resolve on their own or with medication. While a level two ultrasound will focus on the heart and may detect a heart defect, a fetal echo is a more detailed ultrasound of the heart.

A level two ultrasound is usually performed between 16 and 20 weeks of gestation, but the fetal heart is less developed during that time. A fetal echocardiogram is usually performed by a fetal cardiologist around 18-22 weeks when the baby is bigger and the heart is better developed. If necessary, follow-up fetal echocardiograms may be suggested by your medical provider. You can expect fetal echoes to take as long as an hour.<sup>3</sup>

3 Reviewed by Dr. Kan Hor, Assistant Professor of Pediatrics at The Heart Institute, Cincinnati Children's Hospital Medical Center.

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2. **Regular ultrasounds.** To monitor the baby's growth, your medical provider may recommend more regular ultrasounds. Babies with a Down syndrome diagnosis may have a potentially increased risk for lagging growth. Your health care provider can use ultrasounds at specific intervals to assess this risk. If a growth lag is suspected, your provider may increase the frequency of your ultrasounds. He or she may also use ultrasounds to check the development of the baby's organs, including the cardiac and digestive systems.
  3. **Fetal non-stress tests.** Later in your pregnancy, your health care provider may suggest you have regular fetal non-stress tests to monitor the well-being of the baby. This is because research suggests that there is an increased risk of fetal loss for babies diagnosed with Down syndrome. Your provider may also order a test if you sense a reduction in the baby's movements. See "Gaining Perspective on Pregnancy Concerns" on page 20 for more information.

During this test, you will relax in a comfortable armchair with a fetal monitor placed around your belly. You will be given a device and asked to push a button whenever you feel the baby move. Your input and the monitoring results are tracked so that your medical provider can assess the activity level and overall health of the baby.

4. **Other prenatal monitoring.** Because each pregnancy is unique, your situation may prompt increased monitoring or specialized testing by an expert in a different field.

## REFERRALS TO SPECIALISTS POST-DIAGNOSIS

Once the Down syndrome diagnosis has been confirmed, your medical provider may suggest that you see other medical professionals for information or treatment. The following is a list of possible specialists. Whether you are referred to one or more of these specialists will depend on many factors particular to your pregnancy and access to specialized health care.

1. **Geneticist or Genetic Counselor.** Genetic counselors and geneticists will likely give you more information about Down syndrome, the likelihood of recurrence in future pregnancies, and an evaluation of your genetic family history. Genetic counselors can also be reliable resources who can help coordinate care with referrals to local services and connect you with local families and support organizations. In addition, geneticists can provide overall management and coordination of care.

You can also perform your own search at the [National Society of Genetic Counselors](#) or the [American College of Medical Genetics](#).

2. **Perinatologist.** A perinatologist is a medical provider with an expertise in providing specialized care for maternal fetal medicine. Your obstetrician may have referred you to a perinatologist or a maternal fetal medicine specialist due to your age, screening test results, family history, or confirmation of a Down syndrome diagnosis.
3. **Developmental pediatrician.** To provide you with more information about Down syndrome, your medical provider may refer you to a physician with expertise in treating children with developmental delays. You may also be referred to a Down syndrome clinic if one is

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located in your area. See “Finding a Down Syndrome Clinic” on page 63 for more information.

4. **Pediatric cardiologist.** Your medical care provider may refer you to an expert in cardiology for a consultation and fetal echocardiogram. See “Heart Defects” on page 50 for more information.
5. **Gastrointestinal (GI) specialist.** Your medical care provider may refer you to a GI specialist for a consultation and possible follow-up care. See “Gastrointestinal Issues” on page 49 for more information.
6. **Lactation consultant or similar expert.** If you wish to breastfeed your newborn with Down syndrome, a consultation with a lactation consultant, occupational therapist (OT), or speech therapist who is knowledgeable about Down syndrome or cardiac issues may increase the chances of a successful breastfeeding experience. Meeting with an expert prior to the baby’s birth may help you develop a plan. See “Preparing for Breastfeeding” on page 43 for more information.
7. Other specialists. If other issues develop during your pregnancy, you may be referred to an expert in the appropriate field.



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## EVALUATING YOUR MEDICAL PROVIDER

Most pregnant women are typically seen by an obstetrician, a group of obstetricians, or a midwife throughout their entire pregnancy. These providers usually have extensive experience in treating pregnant women and delivering babies. However, a Down syndrome diagnosis adds an additional layer to the typical treatment plan and may prompt you to ask your provider and yourself some of the following questions:

1. *What has been your provider's experience delivering babies with Down syndrome or other prenatally diagnosed conditions?*

The first consideration when evaluating your medical provider is based primarily on their training, skills, and experience to meet the needs of a specialized pregnancy.

2. *How is your provider's responsiveness in coordinating care, sending timely referrals, and communicating with other specialists?*

It is possible that you will receive "co-care" from more than one medical professional. For example, you may receive routine pregnancy monitoring and blood work from your obstetrician or midwife, but specialized monitoring like ultrasounds and non-stress tests from a perinatologist. These professionals will work together to monitor your baby's health and may discuss recommendations for changes to the pregnancy management plan or birth plan.

3. *What is your health care provider's reaction to the diagnosis?*

Many mothers report that their health care providers were supportive in pregnancy post-diagnosis — delivering care and providing advice that

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was non-judgmental and focused on protecting the health of the mother and baby. Others have reported difficulties post-diagnosis, including insensitive comments or negative attitudes about the pregnancy.

If you are uncomfortable with anything your health care provider has said, you can discuss these issues with him or her, explaining how words impact you. It is possible the provider does not realize that his or her words, tone, or attitude have had an impact. For example, a provider may say, "I'm sorry" when delivering a diagnosis, very sincerely intending to be sympathetic. But, you may feel that he or she is behaving negatively toward your baby. An open discussion about your feelings could clear up any misunderstanding.

If you are upset that your health care provider has offered termination as an option, please understand that your feelings are valid — it may be very difficult for moms who are emotionally raw to cope with these offers. However, from your health care provider's perspective, he or she may not have meant to pressure you, but instead meet medical and ethical obligations to inform you of options. He or she does not know what your choice may be and must act carefully. A conversation may clear the air so that your health care provider can assure you of his or her support of your choice.

Beyond the level of sensitivity and misunderstanding, a few health care providers may behave inappropriately when faced with a patient's decision to welcome her baby with Down syndrome. These issues may not be resolvable by discussion, or a mom may feel too hurt or uncomfortable to even want to discuss it. If you find that your health care provider is inappropriately negative towards you, the pregnancy, or Down syndrome, finding a new health care provider is an option. Your local Down syndrome organization may have some recommendations to find a more supportive provider.

You should be able to look forward to a joyful pregnancy and birth, and you are entitled to a provider who will be a valuable partner in that journey.



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## COPING WITH A DOWN SYNDROME DIAGNOSIS

Though the personalities and life experiences of mothers receiving a prenatal diagnosis of Down syndrome are quite different, the emotional journey can be remarkably similar. Most moms say that pregnancy from diagnosis to delivery is an emotional roller coaster. The hardest moments are usually at the time of diagnosis and immediately afterwards, followed by emotional growth and, hopefully, a positive birth experience. This grief process is both expected and very normal. After awhile, most moms can look back and see how far they've come.

### RECEIVING THE NEWS

Odds are that you were dealt a significant emotional blow when you received the news. Moms have used words and phrases such as “devastated,” “blindsided,” and “rug pulled out from underneath me.” Some say it feels like “time stopped.” Some report that after hearing the initial diagnosis, they can no longer absorb the words of their health care provider. Many have reported that the line “before” and “after” is indelibly drawn in their memory. Dr. Brian Skotko refers to this impact as a “flashbulb memory”<sup>4</sup> that can be remembered with perfect clarity decades later.

4 Skotko, B. (2005). Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics & Gynecology*, 192: 670-77.

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Sometimes the way a diagnosis is delivered can cause additional issues for prenatally diagnosed parents. Even a neutral delivery of the diagnosis can unavoidably leave parents emotionally raw as they try to absorb the news. Any insensitivity or pressure can heighten the emotional impact of that diagnosis.

## THE AFTERMATH

In addition to the painful experience of diagnosis, the immediate aftermath may be an extremely difficult time. Parents may be faced with difficult and emotional decisions about options after learning of a prenatal diagnosis. Some of these parents will have chosen prenatal testing for the purpose of getting information rather than making choices. Then, they may be painfully surprised by sudden thoughts about alternatives. With or without these specific thoughts, parents may experience days, weeks, or even months of intense emotional turmoil and self-doubt. Often the sadness is tinged with guilt about having negative thoughts about their child.

Some parents may also feel guilty about a child's diagnosis and blame themselves for their child's condition. Please realize that there is nothing you or your partner did wrong to cause your baby to have Down syndrome.

As you wade through this swirling river of emotions, please know that your feelings are normal, but most parents say that the intensity of these emotions fades over time. You may seek out the advice of experienced parents, and while one part of you hopes that one day you too will have that level of peace, another part may be skeptical. In time, those stories may provide hope for the future and comfort that these feelings will subside. From the intensely difficult time of post-diagnosis, it is very hard to imagine life on the other side. Let the feelings flow — these strong feelings, anxieties, and fears are completely natural. This is a normal part of the grieving process, and most parents move on in time.

## THE PENDULUM

As you progress through your pregnancy, you will likely move away from the very intense emotions, growing toward acceptance, hope, and peace. You may reclaim the joy of pregnancy and the excited anticipation of birth. However, this growth often comes with mixed emotions that can be influenced by positive or negative news at medical appointments, helpful or hurtful comments by those around you, or specific events in your life.

A series of positive events may result in days, weeks, or months of peace. On the other hand, a series of negative events may have a cascade effect, resulting in increased feelings of grief and anxiety. You may feel like you are "back at square one," and you may question yourself, asking, "Why can't I get over this?"

Interaction with other parents may simultaneously reassure you or leave you thinking you are somehow different. "They seem to be fine emotionally, so what's wrong with me? Why can't I accept my child unconditionally the way they do?" Most likely, if you specifically ask these parents about their emotions post-diagnosis, you will hear repeated stories about the emotional trauma of a diagnosis. These parents are usually not much different from

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you; they are just further along in the journey. They also have the advantage of experience and truly knowing their child, with his or her strengths and personality. You have not met your baby yet, so you are coping in a kind of vacuum without a real knowledge of your child's identity.

## **DARK THOUGHTS**

While experiences are similar, there is some variation in terms of emotional recovery time and specific thoughts or fears. Many of your life experiences, especially whether you have known people with Down syndrome, will influence your emotional healing. Some of the many emotions or negative thoughts moms have experienced are:

- Emotional distance from the pregnancy
- The feeling of being pregnant with a diagnosis, not a baby
- Fleeting thoughts that a miscarriage will end this emotional pain and perhaps be better for everyone
- Blaming yourself ("Was it something I did?") or feeling biologically or reproductively inadequate
- Feeling self-conscious, isolated, or judged
- Thoughts of "Why me? Why us? Why my baby?" with the idea that you are somehow being punished
- Topics or words which previously flew under the radar are now sources of emotional pain, such as termination, ridicule of the disabled, or slang words for those with intellectual disabilities

These feelings are common for many expectant moms and do not reflect on how you will be as a parent or your bond with your baby. They are a normal part of the grieving process, and it is important for you to allow yourself to experience these emotions and to forgive yourself for any painful thoughts once you have moved forward.

## **RECLAIMING JOY**

This swirl of negative thoughts and emotions may often exist simultaneously with positive feelings and hope for the future. You may feel an intense need to protect the baby in utero, seeking out all prenatal monitoring aggressively. You may feel that familiar excitement when the baby kicks, go through a "nesting" phase as you decorate the nursery, have a family discussion about potential names, and have your heart melt when shopping for cute baby clothes. It is hard to imagine in those first few days post-diagnosis, but many moms do reclaim that joy of pregnancy. As you near the end of your pregnancy, you may be very excited about the baby's arrival. Also as birth approaches, you may feel your anxieties increase with a feeling that the baby is safe and warm inside, with the "unknown" lying on the other side.

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## BIRTH AND BEYOND

Research does show that parents who learn about a prenatal diagnosis usually have a better newborn experience than parents who find out the diagnosis after birth.<sup>5</sup> A prenatal diagnosis gives women months to adjust to the idea that their baby has Down syndrome. That way the joy they feel when their baby arrives eclipses the dark times they already experienced prenatally. Many moms report intense feelings of relief and adoration when they finally see their baby for the first time.

However, there are moms who may still experience mixed emotions after the baby is born. For those moms whose babies face medical issues, the long period of time in preparation may strengthen them emotionally. However, even with preparation, NICU stays and neonatal medical issues may continue the emotional roller coaster until life can be more settled.

Generally, the intensity of the prenatal and neonatal time period passes, and life calms down. Hopefully, your prenatal experience will have given you time to experience the bulk of the emotional adjustment, allowing you to experience the full joy of parenting.

## THERAPY DURING PREGNANCY

The long months of living with a diagnosis in a vacuum without a baby to hold can also be emotionally exhausting. It is very important that you take care of your own emotional well-being, especially if there are other ancillary stressful events in your life or a history of mental health issues. Seeking out the assistance of a therapist may be a necessary step for some moms, and can help you welcome your child on more solid emotional ground. Do not hesitate to ask your medical care provider if you feel you are in need of someone who will talk with you about your fears, concerns, and stress.

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5 Skotko, B. (2005). Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics & Gynecology*, 192: 670-77.

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## PROFESSIONAL COUNSELING AND RISKS FOR DEPRESSION DURING PREGNANCY

Prenatal diagnosis and the emotional aftermath can put expectant moms at risk for depression during and after pregnancy, especially if other factors are present, such as previous history with depression or other life circumstances. The umbrella of “perinatal depression” includes both postpartum (after birth) depression and antepartum (prenatal) depression.

In a typical situation, many factors are considered to see if a mom is at risk for or currently feeling depressed. Some useful self-check lists include [The Edinburgh Postnatal Depression Scale \(EPDS\)](#), as well as the [PPD Risk Assessment During Pregnancy](#). As you look at these checklists, you may notice yourself answering “yes” to many of the questions involving sadness, fear, or stress, because these are a very natural result of receiving a prenatal diagnosis. For many expectant moms, family support, local Down syndrome support groups, or on-line support in Down syndrome forums may provide appropriate emotional support. For other expectant moms, an appointment with a psychologist may be needed.

In order to find professional help, contact your doctor for a referral to therapists in your area. You can also contact [Postpartum Support International](#) (1-800-944-4PPD) to track down a local therapist. When you contact them, ask for a therapist trained in “unexpected outcomes” and note that you are coping with a prenatal fetal diagnosis.

Even when professional help is a good idea, many times this is impossible for moms who are limited by time constraints or geography. The [Postpartum Stress Center](#) has on-line support, including tools and advice for self-help and family support, as well as a monitored discussion board.

Note that if you experience suicidal thoughts, you should immediately see a therapist, go to the Emergency Room, or contact [The Suicide Hotline](#) (1-800-SUICIDE).

Based on an interview with:

*Kate DeStefano-Torres, MA, NCC, LPC*

*The Postpartum Stress & Family Wellness Center, LLC Clinical Director*

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## GAINING PERSPECTIVE ON PREGNANCY CONCERNS

One of the difficulties of a prenatal diagnosis may be the anxiety connected to your pregnancy itself. As you adapt to the reality that your baby has Down syndrome, your adjustment period may be marked by concerns for your unborn baby.

Many moms receive or find inaccurate information about the potential for fetal loss. Sometimes moms are told that the rate of miscarriage is very high, or they might not be given any information at all. We hope this section will help you understand the risk, keep it in perspective, and use it to appreciate the value of prenatal monitoring. For more information, see “Monitoring Your Pregnancy Post-Diagnosis” on page 10.

### ASSESSING THE RISK OF MISCARRIAGE

The actual risk for miscarriage in a Down syndrome pregnancy is difficult to identify. The research is somewhat old, and the statistics for Trisomy 21 (Down syndrome) are sometimes reviewed along with other trisomies.<sup>6</sup> The California Birth Defects Monitoring Program notes the study which followed women post-diagnosis from 1989 to 1991 and found that 24% of babies were miscarried or stillborn.<sup>7</sup>

6 Won et al. (2005). The timing of demise in fetuses with trisomy 21 and trisomy 18. *Prenatal Diagnosis*, 25: 608-611; Morris, Walt, & Watt. (1999). Fetal loss in Down syndrome pregnancies. *Prenatal Diagnosis*, 19: 142-5; Bray & Wright. (1998). Estimating the spontaneous loss of Down syndrome fetuses between the times of chorionic villus sampling, amniocentesis and livebirth. *Prenatal Diagnosis*, 18: 1045-1054

7 [http://www.cbdmp.org/bd\\_down\\_prenatal.htm](http://www.cbdmp.org/bd_down_prenatal.htm)

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In addition, data that had been collected for over a decade (1989-2000) in the UK revealed that the average loss rates were 23% after an amnio and 32% after a CVS. The authors of the study also noted that the younger a woman is, the less likely she is to have a miscarriage. In fact, the loss rates can be as low as 19% after an amniocentesis and 23% after a CVS for a 25-year-old woman. Please note that differences between the loss rates are not connected with the procedures performed but may instead reflect the gestational age of the baby.<sup>8</sup>

It is important for women to understand this risk to make sure they are receiving aggressive medical care; however, it is also important not to overstate the risk so moms experience a disproportionate level of fear and anxiety.

## KEEPING THINGS IN PERSPECTIVE

If a mom does have anxiety over the potential for miscarriage, hopefully the actual research will bring some perspective — that the risk post-diagnosis is lower than sometimes quoted and that this research is limited. In addition, the research does not take into account many factors. There have been many advances in prenatal technology, and many of our moms today receive aggressive prenatal monitoring that may decrease the risk of miscarriage. The research also does not separate the data into groups — for example, unborn babies without any identified fetal health issues may have a lower loss rate.

You may be riddled with anxiety about this issue, but please try to stay calm and know that prenatal medical advances continue to benefit this population. The majority of people with a prenatal diagnosis do not have a loss. Please do not allow this concern to dominate your prenatal experience and take away from the joy of pregnancy.

### *Coping with Loss*

Even though many women will continue their pregnancies without complications, there will be some women who experience a miscarriage even though they receive optimal medical care and prepare diligently for the birth of their child. For these women, we offer a separate booklet, *“Coping with Loss,”* on the Down syndrome pregnancy website that gives them additional resources, ideas for creating remembrances of their child, and notes from other moms who have experienced the fetal loss of a child with Down syndrome.

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8 Savva, G. M., Morris\*, J. K., Mutton, D.E., and Alberman, E. (2006). Maternal age-specific fetal loss rates in Down syndrome pregnancies. *Prenatal Diagnosis*, 26:499-504.



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## SHARING THE NEWS WITH FAMILY AND FRIENDS

*“When are you due? Is it a boy or a girl? How did your ultrasound go? How much longer?”*

Our loved ones have so many questions. They care about us. They want to share in our pregnancy, and our answers and smiles give them a piece of our joy. Grandmom and Grandpop, Aunt Susie, our co-workers, and the neighbors next door — they all want to know that everything’s okay so they can share our relief. But what if everything is not “okay?” What if you’ve received news that your child will not be the “typical” child you planned? What if you are crying so hard that your eyes feel like sandpaper and it’s hard to talk? They’re still going to ask questions, and they’ll still look to you for the answers, even though you may feel completely unprepared.

### WHOM TO TELL?

There are a variety of approaches by moms whose babies have received a prenatal diagnosis. Many tell everyone they know, even strangers who ask about the baby. Telling people gives our loved ones time to adjust and accept the diagnosis, hopefully allowing them to welcome the baby at birth without reservation. Others tell no one, seeking to avoid unwanted comments and not wanting their child to be prejudged before birth. This allows loved ones to receive the news after they have already met the baby. Other parents make choices about which people to tell, whether it is immediate family only, or extended family, or good friends. This may be the first of many

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decisions you make concerning your child that specifically reflects your personal feelings, and your knowledge of your loved ones.

Our suggestion is to make a deliberate choice about whom to tell. Some questions you and your partner may ask yourselves are:

- Do I have a supportive family? Will I need their full support during this pregnancy? Do I want my loved ones to “hit the ground running” after the baby is born?
- Do I have an intrusive family? Will they pester me with questions or berate me for my decisions?
- Does my family have an archaic view of Down syndrome?
- Have any of my family members dealt positively or negatively with Down syndrome or other disabilities in the past?
- Does my family have experience with people with Down syndrome? Will they be able to help with insight?
- Will telling people make me uncomfortable? Am I afraid of social awkwardness or always having an “elephant in the room”?
- Will keeping it to myself make me feel like I am ashamed?
- Are there family issues such as marital discord or recent death or injury which would make “telling” particularly painful or awkward?
- Am I particularly sensitive to others talking about my pregnancy?
- Do I gain strength and comfort from talking things out with friends or family?

Considering these different questions beforehand will allow you to develop a strategy and make a purposeful choice about who will participate in your prenatal experience.

## WHAT TO TELL?

*“Our baby has Down syndrome.” “Your first grandchild has an extra chromosome.” “The 1 in 40 odds they gave me? I was the one.”*

What do you say to these people you depend on for love, support and guidance? We suggest that you be honest about the unexpected news, your emotional state, the fact that you are learning, and your hope for the future. Here are some ideas broken down in parts:

**Intro:** Hello to friends and family (or coworkers, neighbors, employees, etc.).

**Reminder:** As many of you know, we are expecting our baby on DUE DATE. We have learned this baby is a boy/ girl, and we have named him/her NAME. We are so very excited about this addition to our family. (Then, add any personalized details you want to share.)

**Update:** We have recently learned that our sweet baby has Down syndrome (and whatever ancillary issues if any). We learned the results through a genetic test called an amniocentesis/CVS, which is virtually 100% accurate.

**Emotional state:** Of course this news has left us anxious, upset, and shocked. We are still adjusting. If you see us, we may still be showing signs of shock, but we have learned from other parents that we will move away from this time of turmoil to a place of excitement and amazement. One thing

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we know for sure: we love our baby boy/girl, and we hope you will join us in welcoming him/her.

**Learning:** We know that you must have many questions, and we will try our best to answer, but we have a lot to learn in the next few months about Down syndrome. We have already started to research, and you can look at [DownSyndromePregnancy.org](http://DownSyndromePregnancy.org) for some basic information for friends and family. Some of the most important things we have learned are that each person with Down syndrome is a unique individual, and that recent advances in medicine, education, and acceptance have greatly improved the lives of people with Down syndrome. More importantly, we have learned that our son/daughter will live a rich and rewarding life, and will enrich ours as well.

**What to say to us:** We know many of you may not know what to say to us when you see us — and we understand. We're not sure we would have known what to say either. We would appreciate if you could avoid saying, "I'm sorry." We have heard from other parents that they hear this a lot, and it tends to hurt after awhile. We have listed a website below which might help.

**Closing:** We will keep you updated about any issues that come up and when our baby arrives. Thank you all so much for your love for us and for welcoming our little one.

The ideas above give you a generic outline for telling people the news. Of course, your approach will also be individualized depending on your personal circumstances and comfort level.

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For a basic description of Down syndrome and suggestions for your loved ones about how to support you, please see [“Your Loved One is Having a Baby with Down Syndrome”](#) on the Down syndrome pregnancy website.

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## WHEN TO TELL?

Depending on when you have received the news, you may be facing a very long time in pregnancy post-diagnosis. It is possible that you have already shared your news with loved ones — many people reach out for support right away. If you have yet to share your news, you will need to decide whether you want to talk about your diagnosis now or later. You may also wish to wait until you have more information about Down syndrome, ancillary issues, or after you've been through the most difficult emotional adjustments.

Even though you may not be able to conceal your emotions early on, a delay in telling your loved ones will give you the benefit of being able to gather your thoughts, rein in your emotions, and deliver the news from a position of relative strength. It will be easier for you to craft your message for the right tone and level of information. As you make your decision, consider such things as how often you see your loved ones, their level of curiosity, and your emotional state.

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## WHERE TO TELL?

Many parents say that sharing the news in person is best done in a private setting where you can gather your thoughts and be deliberate about how you present the news. Then, you can allow your loved ones to react without distractions.

Our advice is to avoid sharing the news at large social events such as weddings, funerals, or family gatherings. You may not have confidence in your own ability to “keep it together” while discussing the diagnosis, and at boisterous or strained social events, people may be surprised at the news and unable to adjust quickly enough to know the proper things to say. On the other hand, smaller, intimate settings allow your friends and family to pick up on your cues, concentrate on what you are saying, and sometimes give more appropriate responses.

## HOW TO TELL?

*In person. Phone call. E-mail. Let the word spread.*

These are essentially your options for how to tell people the news. You may find that informing the people you know may involve multiple methods.

Telling your closest loved ones in person may be an option if they live close to you, but that could cause some issues depending on your emotional state. If you have waited until the initial emotional impact has faded, you may be able to have a calmer discussion, but be prepared for a potential surge of emotion when you see their reaction.

Phone calls allow you to tell those closest to you one on one, and give you an escape hatch if the conversation is overwhelming. Phone contact also allows you to reach close relatives despite great distances. However, you will need to be able to speak coherently, which may be difficult if you are emotional.

Both in-person and phone contact create an opportunity for loved ones to comfort you in real time, but these methods do leave you vulnerable to the unpredictability of the immediate reactions of others. People reacting to unexpected news can sometimes do or say things that hurt us.

Sometimes you can tell a select group of people and ask that they pass on the news. This allows others to react away from you and compose themselves before talking to you. It also saves you from the potentially uncomfortable task of telling, or the tediousness of repeating it over and over. It can also make you feel like people are talking about you, and others may pass on misinformation, so be aware of these possibilities. You may also be unaware about who does or does not know, which may lead to some awkward situations in the future.

A group e-mail will allow you to craft the message and control the tone, and will avoid a one-on-one emotional meeting. It is also something that can be forwarded so that your message will stay intact. It may not be ideal for your closest loved ones, especially those without e-mail access, but it is a good tool for letting a large group of people know.

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[DownSyndromePregnancy.org](https://DownSyndromePregnancy.org) includes a collection of personalized e-mails that reflect different family situations, faiths, and cultural backgrounds. You are welcome to copy and paste from these sample e-mails.

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## **BEYOND SHARING THE NEWS**

Sharing your news is just the first step in the months of human interaction as you progress in pregnancy post-diagnosis, which can involve many questions and comments after people hear about the diagnosis.



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## DEALING WITH COMMENTS

As your pregnancy progresses and more people are aware of your baby's diagnosis, you will hear comments that give you strength and support and help you cope with your new reality. However, other comments might make you uncomfortable. Of course, expectant parents react in a variety of ways. You may be the type of person who is not sensitive to comments at all, or you may be the type of person who has never been sensitive, but you feel more fragile during your pregnancy. This section aims to empower you to respond to comments in a way that is appropriate and informative, while knowing that your emotional reaction is understandable and often justified.

Our approach is simple: plan for the comments and prepare an intelligent and confident response — your “spoken response.” But let your mind roam free and express to yourself or in a written journal your gut-reaction to these comments as an outlet — your “unspoken response.”

Remember that most people do not mean to hurt you. Most people are kind-hearted and only wish to support you. However, they just don't know how their comments sound to your ears or the emotional turmoil you may be experiencing. Often the speaker has no idea that this is the 100th time you've heard this. While many expectant parents have been tongue-tied from surprise and anxiety by some comments, hopefully, you will be prepared.

As you read these suggestions, please do not feel that you “must” respond this way. Some moms feel it is unfair to expect them to think of others' feelings at this time when their emotions are raw. And we agree that if there is any time in your life that your loved ones should be “walking on eggshells”

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around you, this is the time. However, many others want ways to respond and cope that allow them to vent privately and educate those around them.

## TERMINATION COMMENTS OR PRESSURE

Whether moms are pro-life or pro-choice, many can be hypersensitive to discussions about termination. This may be because of the specific termination offers moms have received or a sense of unease concerning society's view of disability and prenatal diagnosis. When combined with the emotional roller coaster and general anxiety, many moms become very sensitive to casual comments that may have passed their notice before. They can feel particularly sensitive to pointed comments directed at their choice to welcome their child with Down syndrome.

**Comments Questioning Your Decision:** It may be the blunt, *"You're not having an abortion?"* or the paternalistic questions, *"Have you thought this through? Have you thought about your other children?"* It could also be the belief of a close relative that you should terminate and use some negative comments to pressure you.

**Spoken/Written Response:** *"Please allow me to interrupt you. I am the mother of a child with Down syndrome. He or she will be born soon. I will not be terminating this pregnancy. This is a decision I have already made. Despite my certainty, this is still the most emotional time of my life, and I'm trying really hard to keep it together. Your comments about termination are making it more difficult for me, and I'm asking you to please stop. I have many concerns and fears, but I am reassured by other parents that our child will bring us great joy and will be a valued member of our family. I am learning about the research showing a positive impact on family, including a lower divorce rate, and resiliency and compassion in siblings. I have a lot more to learn, but I have already made my decision. If you can not support me or help, please don't say anything at all."*

**Unspoken Response/Vent:** *How could you do this to me? Can't you see my pain? Why do you want to pour salt in my wounds? What motivates you? Are you just clueless or are you actually trying to kick me when I'm down? I feel like there is a sign over my head saying, "Please talk to me about termination." How is this even your business? Your comments insinuate that I don't know what I'm doing — don't you realize how insulting that is? And now I have to worry about whether you'll ever accept my child. I want to avoid you for the rest of my pregnancy. Is that what you want?"*

**Spousal/Partner comments:** A lack of spousal or partner support can be particularly painful and difficult. On one hand, they are entitled to their own emotions, fears, and concerns. Any response has to reflect a respect for their emotions. They may need more time to adjust, and hopefully will come around. However, they should not make the emotional pain worse through comments or pressure.

**Spoken/Written Response:** *"I know how upset you are, how fearful, how worried. I know you are thinking we can't possibly do this. I have a lot of the same fears and worries. I know I'm making a decision that impacts you greatly, and that might cause you to have some anger if you don't agree. But this is my body, my child, and I simply can not do what you ask of me. Please understand that this child is coming, and I'm trying to cope with that reality. The arguments, the pressure, the comments — they are hurting me and hurting our relationship."*

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*You are entitled to your feelings, but I'm hoping you will be able to accept and embrace this child for the sake of our family. I know that may take time, but in the meantime, please stop trying to make me do something that I won't do. It hurts too much."*

**Unspoken Response/Vent:** *You are supposed to be helping me through this! I feel so alone, and the one person who is supposed to be in my corner is hurting me. Please stop. I need you. How can I do this on my own? Please, please stop saying things. Please accept our baby, your baby.*

## RUDE COMMENTS

Expectant moms have reported a variety of rude comments, from people saying, "I'd have terminated," or "better you than me," to "it's your fault because you are too old to have babies." Hopefully, you will not be on the receiving end of any such comments, but if you are, you may feel that responding to the comments will only lead to social conflict. As such, you may feel you are the "bad guy" if you address the comments and may keep your reactions to yourself. Then, you may replay the comments later and have some "what I wish I said" moments. We've all been there, and there is no predicting the particular comment you may receive, but practice anyway — thinking ahead may allow you to adapt quickly.

**Spoken/Written Response:** Some response examples include: "I know everyone has opinions about what they would do, but it's not the best time for me to hear it." You can also simply respond, "That was a horrible thing to say." Then you can follow up by saying, "I know you don't mean to hurt my feelings, but it really does hurt to hear you make that comment. This is a really rough time for me, but I already feel enormously protective of my baby. I don't want to make anyone feel awkward, but it puts me in a difficult situation."

**Unspoken Response/Vent:** *What is wrong with you? Is my baby's diagnosis an open invitation for you to say whatever pops into your head? Haven't you ever heard of "audience appropriate" remarks?*

## OPTIMISTIC COMMENTS

### *Diagnosis Optimistic Comments*

These comments are usually intended to be hopeful but can be very damaging to the mom adjusting and accepting her baby's diagnosis. They may include an adamant denial, "I know this baby does not have Down syndrome," or sincere repetition of things they've heard, "Aunt Susie's friend was told when she was pregnant that the baby had Down syndrome, and he was just fine when he was born." They may be shots at the medical community, "Doctors don't know everything," or uninvited appeals to a higher power, "We will pray that the Down syndrome goes away." Again, these loved ones are very sincere in their efforts to make you feel better, but often your reaction may be a stifled anger or resentment which is difficult even for you to understand or articulate to yourself.

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**Spoken/Written Response:** *“Well, thanks for thinking of me. But one thing we have accepted is that our baby absolutely has Down syndrome. We had a genetic test, which shows absolutely that the baby has an extra 21st chromosome. I know sometimes people have screening tests that show an increased chance of Down syndrome and then the baby is born without it. Sometimes that is passed down the line and translated to “the doctors were wrong.” They were not actually wrong — it was just a screening test in those cases. But in our case it is more than a screening test. The genetic testing on the baby’s amniotic fluid is well over 99% accurate. I know there are extremely rare times when there is a false positive, but it is extremely unlikely and focusing on that extremely unlikely possibility is actually harmful to our emotional well-being. As part of acceptance, we have realized that our baby has had Down syndrome since the moment of conception. She is who she is. We hope that you will be able to accept her, but comments focusing on her not having Down syndrome make us fear you will not accept her.”*

**Unspoken Response/Vent:** *Can’t you see I’m adjusting to this diagnosis? How exactly do you think I’m supposed to understand your statement — that you are reinforcing how horrible you think this diagnosis is, or that I should forget all of my progress towards acceptance with your unfounded idea that it might be wrong? I feel like I’m climbing “Mount Acceptance” and friendly, well-meaning people keep popping up and telling me to stop climbing. It’s not helping me.*

### *Parental “Fluff” Comments*

These comments are also usually shared by well-meaning people who are trying to boost your morale, but they can sometimes be problematic. You are at your most vulnerable, feeling lost and afraid, and emotionally volatile. In an attempt to comfort you, people tell you that “*special babies are sent to special people,*” or that you are amazingly strong, or you were picked. One parent was even told, “*You shouldn’t be worried or sad. You should feel blessed that you were chosen to be this little girl’s parents.*” The person speaking truly feels these comments are comforting, and, to some of our moms, they are. But other moms react very strongly to comments that qualify who they are based on a diagnosis.

**Spoken/Written Response:** *“I know you are trying to make me feel better right now, and I do appreciate it. I’m really thankful that other parents have told me they have experienced the same emotional turmoil, and that it is perfectly normal. I know I’ll move on from these feelings, especially when I see the baby, but I’m just not there yet. Every time someone tells me how special I am, it makes me feel inadequate and not up to the task.”*

**Unspoken Response/Vent:** *I’m not any more special, strong, or blessed than I was a few months ago, except right now I feel lost, afraid, and wonder, “Why me?” or “Why my baby?” I’m scared about the rest of this pregnancy, what will happen after birth, and the future. I can’t just turn those feelings off. Please don’t put me on a pedestal. I feel really bad right now, and a pedestal is the last place I want to be! Rather than making me feel better, it makes me feel worse. It makes me think you are making everything right in your world by classifying me as the one who is “supposed” to have a child with special needs. Well I don’t feel like I fit the role you are writing for me. Let me feel what I want to feel — don’t tell me how I’m supposed to feel or how I’m supposed to see myself.*

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## Down Syndrome “Fluff” Comments

Many people will try to comfort you with positive comments about Down syndrome, and many expectant parents will appreciate these words. However, sometimes the comments don't sound quite right, especially when said by someone who has not been where you are. These comments may include remarks that Down syndrome is “no big deal” or “a blessing” or that “people with Down syndrome are always happy, loving, and innocent.” Many of these things you may experience with your child. Likely one day you too will see your child as happy, loving, a blessing to you and your entire family. However, sometimes these comments can feel like the individuality is being taken away from your child, or that they are losing their complexity as an individual. They may seem like they are being described as two dimensional rather than complex people capable of a vast array of emotions like everyone else. This certainly is not what the speaker intends, but often it can be what we hear. It can also make you feel like they are telling you your grief is unwarranted or silly.

**Spoken/Written Response:** *“Well, talking to parents I've learned that their kids are wonderful, and, just like other kids, they have the full range of emotions, from happiness, to anger, to love, to sadness. We'll get to know her personality when she comes out to meet us. I'm glad you are so willing to accept our baby for who she is. We are still grappling with what issues she may face later, so we are still a little apprehensive. Thanks so much for supporting us.”*

**Unspoken Response/Vent:** *I know you mean well, but I'm not giving birth to a doll. She's a human being, and she will be uniquely herself. I may still be learning about Down syndrome, but I know enough to know people with Down syndrome are not all the same. And it's easy for you to say “no big deal” — you aren't dealing with the collapsing of the future you envisioned for your child and a reconstruction of that future before even meeting her.*

## IGNORANT/ CURIOUS COMMENTS

By ignorant, we mean “unknowledgeable” — not the slang equivalent of “rude.” And yes, we give a lot of slack to the public at large — of course they don't know a lot about Down syndrome — why would they unless they love someone with Down syndrome? But, again, pregnancy leaves you sensitive, and the things you may have once said to another person may now bother you. And the questions — they ask so many questions which you can not answer. Sometimes that can accentuate your own lack of knowledge. Here are a sample of some comments moms have heard:

*“Maybe she won't look like she has Down syndrome.”*

**Spoken Answer:** *“Well, actually mostly she'll look like us. There are also a variety of features related to Down syndrome which she may or may not have, but odds are she'll have some of the features. I've been looking at pictures of kids with Down syndrome. I've seen so many cute children, and I know she'll have her very own, very unique look.”*

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**Unspoken Answer:** *How am I supposed to take that comment? This baby has Down syndrome. Present tense. Now. Your comment implies that “looking” like you have Down syndrome is a bad thing — how is that appropriate to say to the parent of a child with Down syndrome?*

*“Doctors can get things wrong. I bet her heart will heal before she’s born.”*

**Spoken answer:** *“Actually, I do understand that sometimes certain heart defects heal on their own. However, she has something called an AVSD, which is a hole in the middle of her heart compromising all 4 chambers. Doctors assure me that this particular heart defect does not heal on its own, and she will need open heart surgery.”*

**Unspoken answer:** *“You’ll bet” it’ll heal on its own? Because you got your medical degree where? Oh that’s right - from the school of “Some Guy Said.” And I should just put all my eggs in your basket and ignore that pesky cardiologist.*

*“How severe is it?” “Is it a severe case?” or “Maybe she’ll just have a little Down syndrome.”*

**Spoken answer:** *“Well, she has Down syndrome, which means she has an extra chromosome in every cell in her body. With Down syndrome, you either have it or you don’t.<sup>9</sup> We’ll just have to wait and see about the medical issues. As far as cognitive ability, there is a wide variation among the Down syndrome population, and we really won’t know until he’s older what that outcome will be. But the most important thing is that we know he’s going to be cute and lovable when he’s born, so we are pretty prepared for that.”*

**Unspoken answer:** *I can’t believe people expect me to know the answer to this question. He’s not even born yet! How am I supposed to have all the answers? I know this is a version of being supportive, but it makes me feel uninformed. How can I be a teacher when I feel like I’m a student on the first day of school?*

## **INCREASING SENSITIVITY TO INAPPROPRIATE VOCABULARY**

It could be a line in a TV series, dialogue in a movie, slurs in a book, or the slang we hear bantered about by our family and friends. Usually they do not intend to insult people with intellectual disabilities, but certain slang words that are often tossed around casually can be hurtful to the families of people with Down syndrome.

Sometimes it’s actual references to intellectual disability – most often the word “retarded” thrown about by middle schoolers and adults alike. Other times it may be references to “the short bus” or other generalized comments. These may have been words which previously flew well below your radar or that you used in the past. Now, if the conversation around you were in written dialogue form, the words might be highlighted, bolded, and under-

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9 Not applicable for children with Mosaic Down syndrome. This diagnosis could require a more complicated answer. Please refer to [imdsa.org](http://imdsa.org) for more information.

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lined. Their impact can range from discomfort to pain, and often you just do not know what to say. You may feel that saying something will make the other person uncomfortable — you may feel like you are creating a social conflict. But if you say nothing, you may feel like you are not standing up for your child.

First, we will tell you that it's okay not to be the perfect advocate, especially now when you may be feeling vulnerable. It's okay to just walk away, and wait until you have your "sea legs" to take this on. And if these words don't bother you, that's okay too. As you prepare for interaction with the Down syndrome community, you should examine your vocabulary to make sure you are not hurting the feelings of other parents, but there is no rule book that says you yourself should be sensitive to slang.

Second, if the slang now hurts greatly, and you want to say something, your best approach is to be proactive rather than reactive. Sending your thoughts out to loved ones in an organized, thoughtful, and non-judgmental way, that anticipates their responses, will go much further than an emotional "on the spot" reaction. If you have previously used these words in slang, explain that to your loved ones, and ask that they come along with you on your journey towards kinder vocabulary.

If you need some suggestions or guidelines, you can go to [DownSyndromePregnancy.org](http://DownSyndromePregnancy.org) for examples of e-mails that parents have written to loved ones trying to handle this topic gently.



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## PREPARING YOUR OTHER CHILDREN

After adjusting to the initial shock of a Down syndrome diagnosis, you may be concerned about the future for your other children and wonder how a new baby with a disability will impact them. You may worry about whether the siblings without Down syndrome will be teased, feel resentment, get enough attention, get embarrassed, or be impatient when dealing with their brother or sister. These are all real concerns that are likely to happen at one time or another, but research shows that most siblings still say that the positives outweigh the negatives and that there are benefits to having a brother or sister with Down syndrome.<sup>10</sup>

Research also shows that the siblings of children with Down syndrome tend to be more compassionate and well-adjusted.<sup>11</sup> Another study showed that the siblings of children with Down syndrome rated their relationships with friends and their academic performance with the same scores as their peers who didn't have a sibling with Down syndrome.<sup>12</sup>

Some parents also express concern about the impact of a child with Down syndrome on their marriage and the possible ways it might affect the other

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- 10 Skotko, B. & Levine, S. (2006). What the Other Children Are Thinking: Brothers and Sisters of Persons With Down Syndrome. *American Journal of Medical Genetics Part C* 142C:180 – 186.
  - 11 Dykens, E. M. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *Mental Retardation*, 43: 360–364.
  - 12 Cuskelly M, Gunn P. Adjustment of children who have a sibling with Down syndrome: perspectives of mothers, fathers and children. *Journal of Intellectual Disability Research*. 2007;50(12):917-925.

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children. The good news is that the overall divorce rate is actually lower for the parents of children with Down syndrome.<sup>13</sup>

Even though a child with Down syndrome experiences various challenges associated with their condition, their siblings by and large view them as individuals and develop typical sibling relationships that can include rivalries, fierce protectiveness, playfulness, occasional sibling squabbles, and genuine love and respect.

However, this emotional development and maturity is certainly fostered by parents who encourage open conversations, respect, and appreciation.

## TELLING YOUR OTHER CHILDREN

What and when you tell your other children depends on a number of factors, including their age, maturity, disposition, your state of mind, and anticipated medical issues. Children younger than 5-years-old often don't grasp what Down syndrome means and might not notice any difference for a while.

For very young children, some parents choose not to explain until their child is old enough to understand what Down syndrome means; they might reveal the information in steps by explaining that the baby is going to need extra help learning to walk or talk; or they might simply address the most pressing issue by explaining that the baby will need surgery to repair his heart. And yet other parents choose to identify the condition right away and then gradually explain what it means.

Elementary school-aged children can typically understand Down syndrome at an age appropriate level. You might explain to a first-grader that she is having a new brother, which is very exciting. Then you might explain that every person is born with different characteristics, such as eye color, hair color, and height. Then you can say that one characteristic of this brother is that he will have Down syndrome. This usually means that his muscles are weaker, he might have trouble speaking, and it might take longer for him to learn. A fifth-grader, on the other hand, can usually understand an explanation where you talk about how Down syndrome occurs when a person has an extra chromosome and causes developmental disabilities and low muscle tone. Then, you can ask her about her concerns and address them directly.

Some questions to ask yourself before sharing the news with your child:

- Will my child understand if I share the diagnosis with her? If not, should I share the diagnosis in steps that she *can* understand?
- At what level should I present the information to be age-appropriate? How much information should I share?
- What is my emotional state? Should I explain some of my fears and concerns so she understands why I have been acting differently, or should I wait until my emotions have settled?

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13 Urbano, R., & Hodapp R. (2007). Divorce in Families of Children With Down Syndrome: A Population-Based Study. *American Journal on Mental Retardation*, 112: 261-274.

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Consider all these factors when you decide to share the news with your child and then pick a time when you can sit down with her without distractions and address her concerns.

## ADDRESSING CONCERNS

Below are some common concerns expressed by siblings and some sample answers for their questions.

### *Why are you so sad?*

*"Sometimes I might seem sad. This is because I love your brother and worry about him just like I love and worry about you. Your brother will be okay, and I will be okay, but it just takes little while for me to learn and understand what I need to do to help him."*

### *Can I still play with my brother?*

*"It might take a little longer for your brother to learn to talk or walk, but he will do those things. And you can help him. He will have a therapist who comes to the house and teaches us how to play with him, and you can help by playing some of the games the therapist teaches us."*

### *Will he be okay?*

*"Your brother has a heart condition that will need surgery, but once the doctors fix that, he will be a healthy boy and do just fine."*

### *Will you still be around to help me?*

*"Of course, but your brother will need some extra time in the beginning. He might have to stay at the hospital a little longer, and he might need surgery when he is a few months old. This will mean that I will have to spend some more time at the hospital and, of course, a newborn always needs more attention because I have to feed him and change his diapers, just like I did for you. But, it won't take too long for things to settle down and then I will spend time with all of you. While I'm away at the hospital, your grandma will be here to help until I come back, and she will bring you to the hospital to see us."*

## KEEPING IT REAL

It's important to remind your children that a Down syndrome diagnosis is just one characteristic of their brother or sister. They will have lots of questions, and it's important to address them as best you can. However, your children will soon get over the diagnosis and simply see your child with Down syndrome as "Andy" or "Gabby" — just another ordinary member of your family.

So, during pregnancy, you can help your children develop an attachment to their sibling by allowing them to help pick out names, select decorations for the nursery, or buy clothes for their brother or sister. They can write notes

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to the newest member of the family, look over ultrasound photos, and feel your belly when the baby kicks. First and foremost, this new little baby is a member of your family and their brother or sister.

## FINDING SIBLING RESOURCES

You can begin to prepare your children for the arrival of their new brother or sister with the following resources:

### *Books:*

- *Common Threads: Celebrating Life with Down syndrome* by Cynthia Kidder and Brian Skotko

For younger children:

- *We'll Paint the Octopus Red* by Stephanie Stuve-Bodeen
- *The Best Worst Brother* by Stephanie Stuve-Bodeen
- *I Can, Can You?* by Marjorie W. Pitzer
- *My Friend Isabelle* by Eliza Woloson
- *My Friend Has Down Syndrome* by Jennifer Moore-Mallinos
- *My Sister, Alicia May* by Nancy Tupper Ling

For older children and teens:

- *Views from Our Shoes: Growing Up With a Brother or Sister With Special Needs* by Donald J. Meyer
- *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters* by Brian Skotko & Susan P. Levine
- *The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs* by Don Meyer
- *Thicker Than Water: Essays by Adult Siblings of People with Disabilities* by Don Meyer
- *Gifts 2: How People with Down Syndrome Enrich the World* by Kathryn Lynard Soper

### *Other resources*

Conferences and workshops:

Each year the national *NDSC Conference* offers a Brothers and Sisters Conference for siblings entering 6-12th grade. This conference usually includes workshops about different Down syndrome issues, sharing sessions with other siblings, guest speakers, and activities.

Local support groups and hospitals often have activities, support groups, and sibling workshops for siblings also. Check with your local Down syndrome organization for more information.

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Other siblings:

While you can reach out to other siblings at the national conference and at local events, you can also meet other siblings through your local Down syndrome organization or in your community. Sometimes it can help your children to meet other siblings so they can see other families like theirs and that having a brother or sister with Down syndrome isn't totally unique.

## **HAVING MORE CHILDREN**

Some parents are concerned about having other children and their chances of having another child with Down syndrome. By consulting with a genetic counselor or geneticist, you can find out your odds for having another baby with Down syndrome and how you can prepare for the future.

You can also speak with other parents from your local organization who have had subsequent children to find out how they made their decision.



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## CREATING AND EVALUATING YOUR BIRTH PLAN

Many women already have birth plans in mind when they start a pregnancy — whether or not to use pain medication, who is allowed to be present at the birth, and what kind of provider they want to use. Others create a plan as they go along. In post-diagnosis pregnancy, you can benefit from creating or modifying a plan with the diagnosis in mind. Many children with Down syndrome are born at local hospitals with little or no specialty care needed after birth. They have been delivered by obstetricians or midwives. They have been delivered in the regular process and gone home with their parents after birth in the usual amount of time. Other children with Down syndrome have needed medical intervention immediately after birth, have received specialty care by experts, and have spent time in the Newborn Intensive Care Unit (NICU).

In evaluating your birth plan, you might want to think about what you desire for the birth experience, while considering the quality of your birthing facility, the proximity to more specialized care, and the particular issues identified through post-diagnosis prenatal monitoring. There are no “absolutes” for the birth plan in a Down syndrome pregnancy. However, there are some issues you may wish to discuss with your health care provider to assist in developing or altering a plan, and understand that you may have to make a “Plan B” to use if complications develop.

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**Birth facility.** Your health care professional may discuss with you whether the birthing facility you had intended to use will still meet the potential needs of the birth of a baby with Down syndrome. In many cases, you may continue to plan on delivering at your local hospital or other preferred facility, especially if you desire this location, but you should ask what the procedure will be if complications develop before birth or after birth. Some questions to ask your health care provider are:

- Does the facility have a Newborn Intensive Care Unit (NICU)? What level is the NICU?
- If the baby needs unexpected specialized care after birth, is the facility equipped to handle those needs?
- How far is a specialized hospital or Children's hospital? How would the baby be transported? Would your partner or other loved one be able to accompany the baby?
- In the rare case that my baby may need immediate surgical intervention, do you deliver at a facility with a surgeon?

*If your provider does not deliver at a facility with a surgeon, you may need to decide whether to choose a different obstetric care provider or stay with your current provider and possibly have your baby transferred*

The answers to these questions may ease your concerns, help you prepare mentally, or perhaps cause some concern that will initiate a discussion about changing the birth location. Discuss a back-up plan to put in place if complications develop during the pregnancy.

If your baby has a confirmed heart defect, discuss with the cardiologist your birth plan to see if he or she has any suggestions. Even if a heart defect has not been detected, you will presumably receive a fetal echocardiogram from a cardiologist or other qualified professional, so remember to ask questions since some heart defects are not detected until after birth. Some heart defects don't cause issues immediately after birth, while others require immediate attention. Depending on the issues your child is facing, the cardiologist may approve delivery at your chosen facility or suggest delivery at a facility with a pediatric cardiac unit.<sup>14</sup>

If you will deliver at a local facility, you can discuss the following procedures with your cardiologist:

- Will there be an on-site cardiac evaluation to check on a known defect?
- Will there be an on-site cardiac evaluation to check the heart even if a defect is not detected prenatally?
- Will your cardiologist be the person checking on the baby at the hospital? If not, who will be performing the evaluation?
- Will they be able to do an echocardiogram at the hospital? If not, where will you have to go and how soon after birth?

If another specialist has identified other issues with your baby, such as a GI tract issue, you will need to develop similar questions altered to fit that issue to ask that specialist.

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14 Simpson, JM. (2010). Impact of fetal echocardiography. *Ann Pediatr Card* [serial online] 2009 [cited 2010 May 27];2:41-50. Available from: <http://www.annalspc.com/text.asp?2009/2/1/41/52806> and the *Fetal Echocardiogram web page of Cincinnati Children's Hospital*.

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**Delivery plan.** Once you have received a prenatal diagnosis of Down syndrome, you might want to create a delivery plan by discussing with your health care professional what is best for your baby. If you already envisioned a plan, discuss what alterations might be necessary to keep the baby safe. Again, there are no “absolute” answers, just things to think about and discuss with your health care professional.

**Discuss the logistics.** Usually women go into labor naturally, waiting at home as contractions increase in intensity. Your health care professional may have concerns due to the Down syndrome diagnosis or other issues detected prenatally, and may wish to have you at the hospital at the first sign of labor. Ask your provider about how she wants you to proceed.

**Discuss an early delivery.** Once the baby is considered “full term” (between 37 and 39 weeks), some health care professionals will discuss with their patients the advisability of delivering the baby with Down syndrome early. While many babies with Down syndrome have been born naturally on or past their due date, there is a statistical higher risk of fetal or stillborn loss.<sup>15</sup> This risk can be partially addressed with aggressive prenatal monitoring (including growth assessments, non-stress tests, and ultrasounds) to determine the possible need for a delivery sometime before 40 weeks. An induced birth also has the advantage of being scheduled during the day with other potentially needed specialists on hand for the baby. Again, there are no absolutes — this is a decision you should discuss from all angles with your health care provider.

If the baby has a known heart defect, discuss the possibility of an induction/early birth with your cardiologist as well, since higher weight (later delivery) is a concern of cardiologists. You may need to balance different interests.

**Other issues.** Other possible issues may arise, so try to keep track of such concerns in a notebook or folder.

**Write a letter, and address language.** As you think about the issues above, you can write a birth plan letter to your health care provider. Write out your desires, your concerns, your questions. Writing will help you organize your thoughts and keep track of answers. It will also give your health care provider a record of your concerns so that he or she will keep them in mind. You can also address your desire for a pleasant birth experience where all medical professionals use appropriate language. We have written a sample letter for a specific situation which can be found on our [DownSyndromePregnancy.org](http://DownSyndromePregnancy.org). We hope it will help you draft your own letter specific to your situation.

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15 [http://www.cbtmp.org/bd\\_down\\_prenatal.htm](http://www.cbtmp.org/bd_down_prenatal.htm)

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*Should I bank my baby's cord blood?*

Some parents want to bank their baby's cord blood with hopes of possibly treating future medical conditions, such as cancer, diabetes, etc. While people with Down syndrome have lower chances for developing certain tumor cancers<sup>16</sup>, children with Down syndrome do have 1 in 100 odds for developing leukemia.<sup>17</sup>

Even though some parents bank cord blood to possibly treat leukemia if it occurs in later years, Dr. Beverly Lang, pediatric oncologist at Children's Hospital of Philadelphia (CHOP), advises that the cord blood of a child with Down syndrome would not be used to treat leukemia either for that child or a sibling.

Scientists believe that the original cells that cause leukemia in a child with Down syndrome might be present in the cord blood. So, giving cord blood might just be giving back the precursor cells for leukemia. For this reason, cord blood from babies with Down syndrome cannot be used if they go on to develop leukemia later on in life.

If you wish to bank your baby's cord blood for other purposes, you might want to discuss any potential benefits with your obstetrician or pediatrician.

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16 Satgé D, Bénard J. (2008). Carcinogenesis in Down syndrome: what can be learned from trisomy 21?. *Semin Cancer Biol*;18(5):365-71. Epub 2008 Apr 1.

17 [http://www.ndss.org/index.php?option=com\\_content&view=article&id=55&Itemid=75](http://www.ndss.org/index.php?option=com_content&view=article&id=55&Itemid=75)



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## PREPARING FOR BREASTFEEDING

Many expectant parents hope to breastfeed their babies for nutritional and bonding reasons. For the child with Down syndrome, breastfeeding may have additional benefits for oral motor development, as breastfeeding exercises more muscles in the mouth. Breastfeeding also has immunity advantages that benefit babies with Down syndrome, especially if they have cardiac or other health issues.

Many babies with Down syndrome breastfeed with no problems. However, others have difficulty due to a weak suck, sleepiness, tongue thrust, or issues related to heart defects. There are many techniques moms can use to have a successful breastfeeding relationship even with these challenges. We highly recommend that you meet with a lactation consultant during your pregnancy to discuss potential issues and solutions. It is best to meet with someone who is experienced with Down syndrome-related breastfeeding issues, perhaps an occupational therapist or a lactation consultant at a Children's Hospital. Meeting with a professional and developing a proactive plan may greatly increase your chances of a successful breastfeeding relationship.

Many of the general tips and techniques for breastfeeding also apply to breastfeeding your baby with Down syndrome. There is an extensive amount of literature that covers the basics — positioning, skin-to-skin contact, timings of feedings, use of a nipple shield, etc. Particularly if you are a first-time mother, you might want to read the literature and attend a breastfeeding course to prepare.

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You might also want to obtain a hospital grade pump if there are initial health problems or latching problems. If you need to pump long-term, most hospitals also rent high-quality breast pumps for a reasonable price. The cost may also be covered by your insurance, or you can deduct the cost as a medical expense.

If your baby has health problems or latching problems, pumping right away will allow you to maintain your milk supply. There are many ways to keep working on breastfeeding during this time, and you may find your baby will take to the breast weeks or even months later. A breast pump will allow you to provide your baby the benefits of breast milk while keeping up your supply so you can teach your baby to breastfeed as soon as possible.

It is also important to monitor the growth and weight gain of any breastfed infant during the first weeks to make sure the baby is getting enough calories. A lactation consultant or pediatrician may give you additional instructions about how to increase your baby's caloric intake based on the specific nutrition needs of your baby.

A lactation consultant may advise you to pump a little bit just prior to feeding to get the milk flowing, which will make it easier for the baby to nurse. She may also recommend that you pump after a feeding to express some of the fat-rich "hind milk" which you can bottle-feed to the baby, making sure she gets enough calories.

Your pediatrician may also recommend that you supplement with formula. This can meet some concerns about calories or low milk supply. Your doctor may recommend that you mix high-calorie infant formula with expressed breast milk at a specific ratio, giving your baby the benefits of breast milk but rich calories that may help a baby with feeding or cardiac issues.

If you are having difficulties after your baby is born, do not hesitate to contact a lactation consultant, a La Leche League consultant, or a cardiac lactation consultant if one is available to you. Emphasize in advance that you would like to speak to someone experienced in this area. Also, go online and do a search or post a question about breastfeeding. Many moms are happy to share their experiences.

## **BREASTFEEDING RESOURCES**

- [\*Australian Breastfeeding Association\*](#)
- [\*La Leche League\*](#)
- [\*Kellymom links to various print and on-line resources\*](#)
- [\*Children's Hospitals and Clinics of Minnesota: Breastfeeding an Infant with Down Syndrome\*](#)
- [\*Mobi Motherhood: Helping Babies Who Have Down Syndrome Learn To Breastfeed by J. Renee Toth\*](#)
- [\*Center for Breastfeeding Medicine at Cincinnati Children's Hospital\*](#)

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## COPING WITH UNRESOLVABLE BREASTFEEDING CHALLENGES

Some babies with Down syndrome may not breastfeed, even if you have experience breastfeeding previous children. If this is the case, please try not to blame yourself or feel guilty. This can be very painful for women who want to breastfeed, but the important thing is staying mentally and physically healthy, enjoying your baby, and keeping your baby loved and well fed.

Many moms commit to pumping long-term, while others go to formula feeding. Finding what works best for you and your baby is what is most important. Of course, you can also still cuddle and talk to your baby while you bottle-feed, and there are other activities such as oral motor stimulation and infant massage that can strengthen your baby's muscle tone and enhance the bonding experience. For more information about oral motor exercises, you can consult with your baby's occupational therapist and see "What Therapy Can I Do at Home?" on page 59. For more information about infant massage, this [Parenthood article](#) gives you the basics and resources for more details.



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## UNDERSTANDING FIRST YEAR MEDICAL ISSUES

Even though babies with Down syndrome have higher chances for some medical issues, it is important to remember that your baby will likely only have some of those issues or none at all. Also, the majority of these conditions are treatable, and most of the major health issues (including heart defects and digestive issues) can be corrected with surgery during the first two years of life. In fact, advances in healthcare have improved so significantly for these medical conditions that the average life expectancy for people with Down syndrome has almost doubled in the past 30 years.<sup>18</sup>

If your baby has relatively minor issues or no complications, your baby could come home with you at the usual time after delivery. However, it is also possible that other issues may require monitoring, a stay in the Newborn Intensive Care Unit (NICU), or a surgery scheduled for months later.

### EXAMINING YOUR NEWBORN

After your baby is born, your pediatrician or neonatologist will spend time examining the baby. He or she will look for common newborn conditions, such as jaundice.

In addition, your health care provider will likely note any physical characteristics of Down syndrome, including eye shape and epicanthal folds under the

18 Yang, Q., Rasmussen, S.A., & Friedman, J.M. (2002). Mortality associated with Down's syndrome in the USA from 1983 to 1997: A population-based study. *Lancet*, 359: 1019-25.

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eyes, the shape and set of the ears, the nasal bridge and shape of the nose, tongue thrust, fat on the back of the neck, any palmer creases on the hands, a sandal gap between the toes, etc. It is likely that your baby will have a few of these physical traits, but not all.

Your health care provider will also note your baby's muscle tone and joints. Generally, babies with Down syndrome have low muscle tone, sometimes described as hypotonia. They also usually have loose joints. The combination of these two things is a physical indicator of Down syndrome, and also presents a need for caution in the way in which your newborn is held. Proper head support and swaddling are important. Ask your pediatrician for more information.

Then, he or she will also look closely for issues that occur more frequently in babies with Down syndrome, such as heart issues, gastrointestinal conditions, vision impairments, and feeding issues. Your pediatrician will also probably order a complete blood count and an ultrasound of the kidneys.

The baby will also be screened for hypothyroidism and congenital hearing issues with an automated auditory brainstem response (ABR) test. These screens are common for most newborns. During infancy, your baby will also be monitored for infections such as ear and respiratory infections.

Ideally, you will be able to hold your baby after delivery. You can try to nurse the baby in the delivery room if you desire to breastfeed, and take plenty of family photos. However, if your health care provider notices any issues that require immediate treatment, it is possible that the baby will be taken to the Newborn Intensive Care Unit for treatment. So have your partner be very quick with the family camera if needed.

## NEWBORN MEDICAL CARE AND ISSUES

Newborns with Down syndrome may experience some common minor issues, and some may experience more complicated issues. You should also expect that your pediatrician will follow certain protocols for tests and referrals to specialists even if an issue is not detected.

### *Minor Issues*

Your newborn may experience more ear infections, sinus infections, respiratory infections, and constipation issues than babies in the general population. You may find your baby does not have any of these things, but they are more frequent for this population as a whole. Many parents also report a frequent low-level congestion as well, which makes a cool mist humidifier, saline drops, and a nasal aspirator (particularly the NoseFrida) helpful products to keep in your home.

### *More Complicated Issues*

In addition to the regular newborn issues, and the minor issues related to Down syndrome, there are a few more complicated health conditions that your newborn may experience. There are lists generated by the

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*American Academy of Pediatrics* (AAP), the *Down Syndrome Medical Interest Group* (DSMIG), and the *Clinical Practice Guideline for Children with Down Syndrome* that detail conditions and percentages of the population impacted,<sup>19</sup> but we will discuss only some of them based on percentage and newborn status:

**Hearing issues** (approximately 50-75% of children with Down syndrome). Although some of these issues occur when the child is older, newborns should be evaluated for congenital hearing loss with a hearing test. The AAP recommends a brainstem auditory evoked response (BAER) or otoacoustic emission. If this was not done in the hospital, ask your pediatrician for a referral. If your pediatrician cannot see your baby's eardrums because the ear canals are often tiny, or if you suspect any hearing issues, your pediatrician will usually refer you to an otolaryngologist, often called an Ear, Nose, and Throat Specialist (ENT).

**Vision issues** (approximately 60% of children with Down syndrome). Although some of these issues occur when the child is older, newborns should be evaluated for eye issues within the first six months by a pediatric ophthalmologist.

**Heart defects** (approximately 40-60% of newborns with Down syndrome). A fetal echocardiogram during pregnancy will look for defects, but some are detected after birth. A cardiac evaluation and an echocardiogram may be recommended for newborns with Down syndrome.<sup>20</sup> See the "Heart Defects" on page 50 section for more details.

**Thyroid issues** (15% of children with Down syndrome). Although only 1% of newborns with Down syndrome have congenital hypothyroidism at birth, as children grow they may have acquired thyroid issues. Babies should have a blood test at birth, six months, and a year. Hypothyroidism is usually treated with daily medication, but it can be damaging to cognitive function if not treated.

**Gastrointestinal atresias** (12% of children with Down syndrome). See the "Gastrointestinal Issues" on page 49 section for more details.

## FEEDING ISSUES

Some newborns with Down syndrome have feeding and slow weight gain issues after birth. Causes may be sleepiness, heart or intestinal issues, tongue thrust, weak suck, reflux, or some other possibilities. Your baby may eat like a champ right from the start, with no issues. However, it is possible that your baby will have issues with breastfeeding or bottle feeding.

If you wish to breastfeed and are dealing with issues, refer to "Preparing for Breastfeeding" on page 43 and ask to meet with an experienced lactation consultant or other expert.

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19 American Academy of Pediatrics. (2001). Health Supervision for Children with Down Syndrome. *Pediatrics*, 107: 442-449

20 See the Cardiology/ Down syndrome website at Cincinnati Children's Hospital (<http://www.cincinnatichildrens.org/health/heart-encyclopedia/disease/syndrome/down.htm>) and the Trisomy 21 website at Children's Hospital of Philadelphia (<http://www.chop.edu/healthinfo/down-syndrome-trisomy-21.html>).

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For bottle feeding, you can consult with an occupational/speech therapist and your pediatrician who may recommend a specific type of nipple and nipple flow, how often to feed the baby, different types of formula and the amount of formula to provide, and how to prompt the sucking reflex.

Sometimes medical issues may trigger more serious eating issues, and some newborns with Down syndrome may use artificial feeding systems, such as a nasogastric tube (“n-tube”) or a gastrostomy tube (“g-tube”). Sometimes these systems are only needed during a hospital stay, and other times they might be needed longer. Your provider can give you more detailed information if your infant requires an alternative feeding system.

For more details about these artificial feeding systems, you can refer to the [University of Washington](#) website created with a grant from the Maternal Child Health Bureau about feeding pre-term infants.

## GASTROINTESTINAL ISSUES

### *Less Complex Issues*

Some newborns with Down syndrome deal with the same issues as the general population, including such things as reflux. Dr. Len Leshin notes that it is not certain that babies with Down syndrome have gastroesophageal reflux (GER) more frequently than other babies, but that increased frequency makes sense due to the lower muscle tone in babies with Down syndrome. He says that although most babies spit up, it is a problem if the baby is in distress or experiences health issues connected to spitting up. Generally, he indicates that a baby with GER will spit up more forcefully, even vomit, at every feeding. Even if the liquid does not come all the way, things like choking, gagging, prolonged fussiness, or other signs of distress in your baby should mean a trip to the pediatrician or to the emergency room.

For a complete explanation, see [Dr. Leshin’s article on Gastroesophageal Reflex \(GER\)](#).

Dr. Len Leshin also addresses constipation, which is seen more frequently in babies with Down syndrome due to low muscle tone and decreased motor activity. He says that your pediatrician may instruct you to use a stool softening product such as Miralax in your baby’s bottle or a suppository such as BabyLax to get things moving. In addition, pediatricians may simply recommend natural remedies like prune juice with pulp. Dr. Leshin indicates that you should only use these products with the instruction and dosage recommendation of a doctor. He says you should keep your doctor informed about the existence and extent of constipation because persistent constipation can indicate more serious issues such as a rectum problems, a condition called Hirschsprung disease (treatable with surgery), or hypothyroidism (treatable with medication).

For more details, see [Dr. Leshin’s article on constipation](#).

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## More Complex Issues<sup>21</sup>

As explained by Cincinnati Children's Hospital, intestinal atresias have a long-term good prognosis with proper medical care. However, they can present challenges in the newborn stage as parents face the prospect of newborn surgery. An atresia is a blockage, which can happen at various places along the intestinal route, while a stenosis is a partial blockage. These require surgical intervention very early on. With the increasing sophistication of prenatal ultrasound, expectant parents are often advised of atresia during pregnancy, which may alert parents to the possibility of Down syndrome. This allows parents to make decisions about the type of facility where they would like to deliver their baby. If your baby has a prenatally identified atresia, you may want to prepare for both a NICU stay and newborn surgery. Whether prenatally diagnosed or suspected at birth (by physical exam or symptoms such as vomiting or distended abdomen), you can expect a series of tests (among the possibilities are X-ray, upper & lower GI series, and ultrasound) to confirm the diagnosis and see the extent of the issue.

For an explanation of the different types of atresias and stenosis, an explanation of the surgical procedures, and other useful details, refer to this excellent resource at [Cincinnati Children's Hospital](#).

## HEART DEFECTS<sup>22</sup>

It is estimated that 40 to 60% of children with Down syndrome also have heart issues. Many expectant parents learn of a baby's heart defect through fetal echocardiogram, but sometimes a defect may not be detected until after birth. Many of these issues will be treated with only monitoring, and many resolve on their own or with medication. Others can be treated with various procedures, and some may need open heart surgery. The vast majority of issues are resolvable. With medical advancements in recent years, heart issues are less and less of an obstacle for people with Down syndrome.

**Monitoring.** With many heart defects, holes seen in utero or in the newborn period may close on their own. The cardiologist will ask that you bring your child in at certain times to monitor the defect.

**Catheterization Procedure.** In this procedure, a catheter is entered through a vein or artery to evaluate the heart or to fix a defect. Many heart defects are repairable through this procedure rather than open heart surgery. This is usually an overnight stay at the hospital.

**Open Heart Surgery.** Some heart defects are repairable only through open heart surgery. Recovery times may vary depending on the hospital or the child. Babies may leave the hospital as early as three days after open heart surgery, but most parents prepare mentally for a week long stay. Some babies may be in longer if there are complications.

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21 Cincinnati Children's Hospital (<http://www.cincinnatichildrens.org/health/info/abdomen/diagnose/obstructions.htm>)

22 See the Cardiology/ Down syndrome website at Cincinnati Children's Hospital (<http://www.cincinnatichildrens.org/health/heart-encyclopedia/disease/syndrome/down.htm>); the Open Heart Surgery page at Cincinnati Children's Hospital (<http://www.cincinnatichildrens.org/health/heart-encyclopedia/treat/surg/open.htm>); the Cardiac treatment options page at Cincinnati Children's Hospital (<http://www.cincinnatichildrens.org/health/heart-encyclopedia/treat/default.htm>); the Trisomy 21 website at Children's Hospital of Philadelphia (<http://www.chop.edu/healthinfo/down-syndrome-trisomy-21.html>), and "The Heart Book" by the Cardiac Center at Children's Hospital of Philadelphia (<http://www.chop.edu/export/download/pdfs/articles/physician-referral/cardiac-folder.pdf>)

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If you bring your baby home for months prior to open heart surgery, your cardiologist will monitor your baby's weight and health with regular visits. Routine visits will include a physical exam and questions about the baby's sleep and eating habits. Depending on your baby's situation, your cardiologist may conduct an EKG, perform an echocardiogram, or prescribe medications at any visit. The timing of your child's surgery will depend on a variety of factors, including weight and signs of heart issues, such as excessive sleepiness, difficulty eating, blue skin tone, etc. A pre-surgery visit may involve a physical exam, blood work, echocardiogram, and an X-ray.

If your doctor has already identified a heart defect that may require surgery, you can also contact your local Down syndrome organization to connect you with other parents whose babies experienced similar issues. They can also offer tips to help you prepare for surgery and give you more information about your local hospital and services.

Please see the following resources for new and expectant parents dealing with cardiac issues:

- [Cardiology/ Down syndrome website at Cincinnati Children's Hospital](#)
- [CongenitalHeartDefects.com](#)
- [Congenital Heart Information Network](#)
- [Yahoo Down syndrome heart group](#)
- [Baby Center "Babies and Children with Heart Conditions" discussion board](#)
- [Cardiac Center at Children's Hospital of Philadelphia \(CHOP\)](#)
- [CHOP cardiac glossary](#)

## PREPARING FOR SURGERY OR A NICU STAY

While many babies go home without a NICU stay or surgery, others will spend a few days or weeks in the NICU. Complications such as prematurity may require an extended stay. The NICU or surgery may be stressful for parents, especially mothers whose hormones are adjusting after birth and who may be in physical discomfort.

With beeping monitors and people around constantly, many parents experience stress that carries over long after their baby is home. Taking some time to plan ahead may ease some of the stress. It may be helpful for you to plan on a NICU stay or surgery and hope those plans will not be needed.

### *Some Practical Tips:*

1. Set up a [Caringbridge](#) account if you wish to be able to update family members from the computers at the hospital. Caringbridge allows parents to automatically update friends and family about their child's condition without needing to contact everyone individually.
2. You can also recruit extended family or friends who are willing and able to provide some assistance with taking care of your other children. Other loved ones may be willing to help with meals and chores.

[Lotsahelpinghands.com](#) is another helpful online resource to explore if

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you anticipate needing meals or childcare during the hospital stay. This website allows volunteers to sign up on a closed community calendar and receive e-mail reminders.

*Note: We suggest appointing a captain to be your administrator of the site ahead of time. That way your captain can coordinate the logistics so that you can focus on your baby.*

3. Pack or have set aside at home:
  - a journal, camera, and book for reading
  - loose, comfortable clothing or comfortable pajamas for you
  - personal hygiene products
  - healthy snacks
  - a list of your usernames and passwords for on-line web support
  - a laptop computer or handheld device with the necessary chargers
4. Purchase phone cards to call from the hospital, assuming that cell phone use is restricted.
5. If you plan to breastfeed/pump, consider the following:
  - Take literature with you on nursing babies with Down syndrome. See “Preparing for Breastfeeding” on page 43.
  - Ask the hospital staff what their pumping accommodations are: Do they have a pumping room? A pump?
  - Ask if there is a lactation consultant at the hospital who is familiar with Down syndrome and the health issues your baby faces. Meet with this consultant as early as possible so she can help guide you and help interact with the NICU staff if necessary.
  - Ask about breastfeeding policies with babies in the hospital.
6. Have a notebook for medical and medical care provider information. Write the names and titles of all medical care providers, the information they give you, questions you have, etc.

**Ask in advance:**

- What are the visitation rules for parents, grandparents, siblings, and others?
  - Are there rooms for parents available on site, or lockers or other accommodations?
  - Is there parent support on site, such as a family center?
  - Is there an occupational therapist on site to work with your baby?
7. For babies undergoing surgery, think about the following before the procedure:
    - For older babies, bring toys with links to hook to the crib.
    - Ask about the procedures for you and your family to donate blood if you wish to do so.
    - Bring clothing with snaps down the front.
  8. For babies undergoing surgery, think about the following after the procedure:
    - Remember that you will have to lift the baby by scooping under the back rather than lifting under the armpits.
    - Ask how long you have to wait before resuming therapy.

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- Ask how long you have to avoid crowds due to germ exposure.
  - Ask your doctor about follow-up care and removal of stitches.

*Note: Do not be afraid to request that the most experienced medical professional administer to your baby, whether it is a blood draw or something more complicated.*

## MEDICAL RESOURCES

For more information on health issues in the early life of an child with Down syndrome, see the following:

- [AAP Health Supervision of Children with Down Syndrome](#) by the Committee on Genetics in Pediatrics
- [Clinical Guidelines for Children with Down Syndrome](#) by Van Cleve, Cannon, and Cohen in the Journal of Pediatric Health Care
- [NDSS Healthcare Associated Conditions](#)
- [Medical and Surgical Care for Babies with Down syndrome](#) by Philip Mattheis, M.D. and Susan Eberly

As you prepare to welcome your baby with Down syndrome, it may also be useful to start a binder for medical information, where you can keep important records, test results, and questions for your pediatrician. You may wish to include the following very useful checklists and charts:

- [Down Syndrome Growth Charts](#) — Print these out and take them with you to your pediatrician just in case he or she does not have them. These are fairly outdated from 1988 and are currently being revised by Dr. Mary Pipan of Children's Hospital of Philadelphia.<sup>23</sup>
- [Interactive Growth Chart](#) from MedCalc — Plots your child by weight and height. You can input your child's data and plot their growth curve.
- [Down Syndrome Health Checklist from Down Syndrome Quarterly](#) — Print this list and take a copy to your pediatrician just in case he or she does not have it.
- [Down Syndrome Developmental Charts](#) from Down Syndrome Online — Print this out for yourself and a copy for your pediatrician just in case he or she does not have it.

## CONCLUSION

Many of these different conditions may be detected prenatally during an ultrasound, and others might only be apparent after birth. If you know about a suspected condition beforehand, you can take the opportunity to prepare for the experience by researching the resources. Otherwise, you can generally prepare ahead of time for a NICU stay just in case. The most important keys are that your child is an individual and that most of these issues, while challenging, are also treatable.

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23 <http://www.chop.edu/service/trisomy-21/our-research.html>



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## FINDING SERVICES

After receiving a prenatal diagnosis, many parents start to wonder about the nuts and bolts of providing for their child with Down syndrome. Questions range from “How will this impact my health insurance?” to “What kinds of therapy do children with Down syndrome need?”

The good news is that there are many different services and programs available for your child, but the bad news is that finding those services can be confusing because they vary widely and are called different names in different places. Fortunately, there are a variety of resources you can turn to for more information. A hospital social worker can be an excellent resource to help connect and explain all the social service options available to you. Other resources who can guide you through the maze of services in your area include parent experts, an Early Intervention (EI) case worker, a pediatrician, a local Down syndrome organization, a genetics clinic, or the local health department. You can also find a list of state resources under the State Specific Resources on the [NICHCY website](#).

If you would like to use some of these resources to do preliminary research during your pregnancy, you may want to start a research file for this information. It will make contacting these organizations much easier later. Below, we provide a general explanation of these different services so you can understand some of the basic jargon and acronyms and where to begin.

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## HOW DO I MAKE SURE MY CHILD IS COVERED BY HEALTH INSURANCE?

### *Private Health Insurance*

Group health insurance plans, including COBRA policies, are required to cover children with Down syndrome — just like any other child added to the plan. If you have a family insurance plan through your employer, it is likely you have an adequate group health plan that will cover your child. However, individual private policies have generally denied coverage for children with Down syndrome in the past on the basis of it being a pre-existing condition. The new 2010 healthcare legislation is intended to prevent these types of exclusions, but it is too soon to tell exactly how health insurance companies will interpret the new regulations.

### *Children's Health Insurance Program (CHIP)*

Another health insurance option available to children with Down syndrome, as well as all qualifying children, is health coverage through a state Children's Health Insurance Program (CHIP) program, which can provide free or sliding-scale fee health insurance for children who are not covered by private health insurance. Parents can often earn 200% or more above the federal poverty level to qualify. You can find out more information by referring to [Insure Kids Now](#).

There are also a variety of state agencies that provide support to families of children with Down syndrome — ranging from rural clinics to monthly consultations.

### *Medicaid*

Medicaid is a health care program that is available to people with disabilities in some states. This is a federal program administered by individual states, so there may be some variation in procedures, application processes, and eligibility for Medicaid. Sometimes Medicaid is automatic if your child receives SSI, but other times states will require that you apply separately.

If you do not qualify for Supplemental Security Income (SSI), some states will provide Medicaid to a child with Down syndrome regardless of income. For example:

Some states have what is known as a **"Katie Beckett Waiver"** for children with disabilities, which allows them to qualify for Medicaid based on disability, not income. The "waiver" means the state has waived the income requirement. This Medicaid policy can be used as a primary policy or as a secondary policy to offset costs that are sometimes not covered by your primary insurance (such as therapies or hearing aids).

Other states have specific developmental disability Medicaid programs that are determined by the needs of the child. However, states often have a limited number of slots available for those programs, and you may be placed on a waiting list.

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For a general overview, see [Social Security Online: Benefits for Children with Disabilities](#), or you can find state-specific information about Medicaid for people with cognitive disabilities at [TheDesk.info](#).

## HOW DO I SUPPORT A CHILD WITH DOWN SYNDROME WHEN OUR FINANCES ARE ALREADY STRETCHED?

### *Supplemental Security Income (SSI)*

Families of children with Down syndrome might qualify for SSI if their income is below a certain level. SSI is a monthly payment to your child. While technically you must apply and wait for a determination that your child is “disabled,” Down syndrome usually meets the criteria.

You will generally need to provide records such as a birth certificate, social security number, and medical records including the karyotype (which is the genetic test confirming Down syndrome). You will also need to provide documentation about your household income, which cannot exceed a certain amount — usually the federal poverty level. Your child’s SSI amount may vary from state to state because some states supplement the federal amount.

## HOW DO I MAKE SURE MY BABY GETS THERAPY?

**Early Intervention (EI)**, is a federally mandated program that is administered by individual states, focusing on assisting children with disabilities from birth to three years of age. The administration of this program can vary from state to state, and in some ways from county to county. In most cases, therapists and/or teachers will come to your home (or your child’s day care setting) to provide therapy to your child. The primary purpose is to teach you ways to help your child develop skills. Sometimes there are Early Intervention therapy centers where parents can bring their children. In most cases, therapy is fun and stimulating for your child. There is also a component of family health, where the case manager may check on your emotional health, inquire about whether you need any additional support, and suggest reading materials or activities.

The services and the title of the therapist may vary depending on the structure and policies of your local EI, what your child needs, and what you seek for your child. In the three years with EI, you may add or drop therapies depending on your child’s development. Some EI programs provide your family with one therapist who has training in various fields. Others provide a diverse group of therapists for your child, each an expert in their own field.

*Cost/Parental Contribution:* Some states have EI programs that provide services at no cost to parents. Other plans require some type of parental contribution, usually taking into account family income and family size.

*Your local EI:* In order to get a general understanding of the way EI operates in your area, you should contact your EI provider or review its website. The website and/or state laws and regulations should give you an idea about whether there is a parental contribution and how much that will be. You can

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find a list of early intervention programs at the [NICHCY website](#) by looking at the State Resources for your state under the heading “Programs for Infants and Toddlers with Disabilities: Ages Birth through 3.” You may also contact your pediatrician, ask your prenatal care provider or birthing facility, check your local library, or contact the local health department. They should have information about your local EI. Local parents and Down syndrome support organizations can give more unofficial and sometimes more insightful tips about the local EI provider.

*Taking the first steps:* Making the phone call is the first step. If you reach out when you are pregnant, it is possible that EI will tell you to call back after the baby is born. Sometimes they will agree to give you an overview in person or over the phone during your pregnancy. After the baby is born, the hospital may contact EI through official channels, or you may contact them yourself from the hospital or once you return home. They will set up an initial meeting at your home where you will fill out general forms with your family, income, and medical information. Different parents report different “start” times for EI that will depend on different factors. Very early visits may focus on difficulties with nursing or bottle-feeding, administering medications (if needed) to a baby so young, proper ways to hold and support a newborn with Down syndrome, etc. The focus will grow and change with your child.

Early Intervention serves many different children, some of whom have unexpected developmental delays that require an evaluation process to determine if they are eligible for services. Most states have provisions that make children with Down syndrome automatically eligible for EI. Some states may require that even children with Down syndrome need to be determined as “eligible” for services based on specific delays. Even if your child is automatically eligible for EI, he or she may be required later to participate in an evaluation process for specific services such as speech therapy.

*A Team Approach:* EI is based on a team approach, and you as parents are part of that team. It can be disconcerting for parents to be asked at early meetings, “What goals for your child do you have for the next six months?” or “What do you think about starting with physical therapy one hour every other week?” In the beginning, we would like to respond, “You tell me. You’re the experts. I don’t know anything.” How can we be expected to know what our babies should be doing in a few months?

While this can be a bit strange in the beginning, as the months go on you will get a better sense of your child, her personality, her strengths and weaknesses, and you’ll realize soon that your knowledge of your child exceeds that of the therapists. You spend the most time with her, and you want what is best for her. So although this role of knowledgeable team member may seem uncomfortable at first, you’ll grow into it and eventually you’ll find yourself adding your observations to meetings, telling them what progress you would like to see, and in some cases advocating for services you feel your child needs. These team efforts lead to a plan for your child that is regularly reviewed and updated, called an Individualized Family Service Plan (IFSP).

*Goals and Milestones:* Whether you are an experienced parent or not, most people have a basic understanding of milestones. We know babies smile, laugh, babble, roll over, sit up, stand, walk, run, and talk. Children with Down syndrome usually accomplish these same milestones, but it generally takes longer. You can view the [Motor Development & Self-Help Skills Milestones](#)

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*chart* to see the average age when children with Down syndrome accomplish their developmental milestones.

In observing and assisting your child's early development, you will be keenly aware of and celebrate the small steps leading up to each major goal. Crawling, for example, starts with many tiny steps, such as tummy time, head lifting, an army crawl, and perhaps a bear crawl. It is these smaller steps that are described as goals, along with the larger milestones, and therapists demonstrate the play-based "exercises" you can do to meet these goals.

*Your role:* As the parent, your role in your child's development will be one of observing therapy, perhaps assisting with therapy, reporting new developments to the therapist, learning the techniques the therapist teaches you, and helping your child through directed play. You can request written reports of each session, which you can keep for your own review and show to other therapists so they can provide consistent care. You will participate in the meetings where the team records progress and sets new goals. It is also important to make sure therapy is fun and exciting — and to speak up if it is not.

## WHAT KINDS OF THERAPY WILL MY CHILD NEED?

EI programs vary in both the selection and availability of services. You may have a "jack of all trades" service provider or you may have a variety of therapists. You may see therapists once a month, every other week, once a week, or multiple times a week depending on a number of factors. Here are some simple explanations of some of the potential therapists a child may see:

**Physical therapist (PT):** Focusing on gross motor skills and overall strength. Larger milestones may be rolling over, sitting, crawling, walking, etc.

**Occupational therapist (OT):** Focusing on fine motor skills, including finger and hand dexterity and strength. Areas include switching objects hand to hand, putting things "in" and "out," beading, holding a pencil, etc.

**Speech therapist:** Focusing on the muscles in the mouth (oral motor skills) and leading up to actual speech and articulation.

**Sign language teacher:** Focusing on teaching the child and the family some sign language or gestures to facilitate communication and decrease frustration. Sign language is often used as a step before speech for children with Down syndrome.

**Feeding specialist:** Focusing on feeding issues related to medical or sensory issues.

**Developmental interventionist (teacher):** A teacher trained in serving young children with special needs and educated in a variety of techniques.

Therapists work together towards developing your child's physical, cognitive, speech, and social skills. In infancy, there is huge overlap in the therapy areas, and as your child develops, the skills are dependent on each other. All therapists may try to encourage speech during therapy. Most therapists are able to do rudimentary sign language or gestures appropriate for a toddler. All therapists have a basic understanding of issues with muscle tone, motor planning, and cognition.

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## WHAT THERAPY CAN I DO AT HOME?

*By Sheryl Friess Zellis, Occupational Therapist*

Your baby with Down Syndrome, just like a typical baby, has multiple sensory systems waiting to be stimulated. There are many simple and even fun activities that can be part of the bonding experience and can positively contribute to the growth and development of your baby.

Each time you change your baby's diaper is an opportunity to provide stimulation to his senses. At the same time, you can become more acquainted with your baby and learn what makes him happy and comfortable.

### *Activities to Provide Light and Deep Touch:*

- Gentle massage to baby's arms, legs, trunk, and back. You can do this while rubbing moisturizer on your baby after a bath or just to soothe him.
- Gently rub a variety of soft textured materials on your baby's arms, legs, back, trunk, and cheeks. A soft wash cloth feels very different to a baby than a piece of cotton or a thick towel.

### *Activities that Provide Auditory/Hearing Stimulation:*

- Play a variety of different types of music from classical to children's tunes.
- Sing, sing, and sing to your baby. He loves your voice! Make it high, low, animated and quiet. (Look at your baby's face so he will follow your voice with his head as well).

### *Activities that Are Pleasing Visually Through Baby's Eyes:*

- When baby is on his back, place your face several inches from his. Move from one side of his face to the other side of his face to encourage him to follow you with his eyes.
- Lay baby on his side or belly, and prop black and white bold pictures of simple faces or shapes for him to look at. Be surprised when he "studies" them!
- Make different faces with your face close to baby's face to vary what he is looking at. Eventually, you may even get a smile back!

### *Activities to Stimulate Tolerance to Textures Around and In the Mouth:*

- Gently rub various soft textured materials (washcloth, cotton, blanket), on his cheeks, lips and chin.
- Place gentle kisses around the mouth, cheeks, and neck.
- Gently massage moisturizer on baby's cheeks and chin.
- Rub your clean finger (with closely clipped finger nails), over baby's lips, inside the mouth on his gums and inner cheeks.

In summary, any of these activities will encourage wonderful responses from your baby and make you look forward to diaper time! Choose a few each time and enjoy your baby!



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## UNDERSTANDING COGNITION AND THE FUTURE

The truth is that it is impossible to predict cognition before birth, but the great majority of people with Down syndrome have mild to moderate intellectual disabilities. The population has made great strides in the last few decades, mainly due to medical advancements (which benefit cognitive development), improvements in education and inclusion, and early intervention therapies.

More recent benefits to cognition include greater education of parents and more research into how children with Down syndrome learn. For example, we now know that sign language or gestures can improve early communication speech skills, that learning to read sight words very early with the right methodology improves speech and overall reading skills, and that math taught certain ways makes more sense for people with Down syndrome. See [DownsEdUSA](#) for more information about educational research.

Much of the success for children with Down syndrome depends on a combination of their cognitive ability, their individual strengths and challenges, the opportunities a specific community provides, and the education and influence of parents.

The healthiest outlook may be to influence the factors over which you do have control to foster an atmosphere where your child has the best chance to thrive. Accept your child regardless of his or her potential “outcome;” and enjoy your child for his or her specific and unique personality.

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## FINDING EDUCATIONAL TOOLS

If you would also like to research other ways to help your child, there are many books, products, and resources to help a baby with Down syndrome to start learning right from the start, including the following:

- *Gross Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals* by Patricia C. Winders
- *Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals* by Maryanne Bruni
- *Toys R' Us Toy Guide for Differently-Abled Kids*  
Includes a catalog for stimulating toys to meet the goals of Early Intervention.
- *"Beyond Play" website*  
Includes a catalog for stimulating toys to meet the goals of Early Intervention.
- *Able Play*  
Includes a catalog for stimulating toys to meet the goals of Early Intervention.
- *Lekotek (available in select locations)*  
Includes a library of educational toys.
- *Signing Time*  
Includes videos, flashcards, books, and music aimed at teaching American Sign Language (ASL) signs to a young child.
- *See and Learn Kits*  
Materials aimed at teaching young children with Down syndrome speech, reading, and cognition skills.
- *Talk Tools website*  
Includes a catalog to purchase items for your baby to encourage speech and focus on oral motor stimulation.

These resources can also provide great gift ideas for family and friends.



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## GETTING MORE SUPPORT

As you progress through your pregnancy, you may find it helpful to reach out to professionals, local Down syndrome organizations, or other parents to assist you through this adjustment period and prepare you to welcome your child with Down syndrome. For many parents, this is a difficult step that may be best left to a later stage or after the baby is born. Other parents may crave a connection with experienced parents right away and will aggressively seek out what they need. Still others may benefit from support, but are uncertain of the landscape or where to turn. Many are not comfortable in groups since their child is not yet born, or uncomfortable with the possibility of an emotional reaction in front of other parents. They may feel that their discomfort or sorrow will be received as an insult to other parents.

Please think about your options for support, and consider your own comfort levels. As you do so, please understand that all of the parents have been through the adjustment to a diagnosis, and an increasing percentage have experienced a prenatal diagnosis. They truly understand the emotional turmoil of a parent who has received a new diagnosis. While they may be all smiles today, most will gladly share with you stories of the dark times post-diagnosis, and understand your current feelings.

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## FINDING GENETIC COUNSELORS AND GENETICISTS

A genetic counselor is trained to offer you a more comprehensive explanation of Down syndrome after you receive a confirmed or suspected Down syndrome diagnosis. Even though your health care provider likely has a basic medical knowledge of Down syndrome, a knowledgeable genetic counselor will be able to provide a broader view about life with Down syndrome, including detailed information about services, modern advances, and potential outcomes.

You can also perform your own search at the [National Society of Genetic Counselors](#) or the [American College of Medical Genetics](#).

## FINDING A DOWN SYNDROME CLINIC

Sometimes a regional area will have a Trisomy 21/ Down syndrome clinic. If you need information about Down syndrome while you are pregnant, you may wish to contact them for an appointment. If you feel it may be helpful, you may wish to inquire about a support group through the clinic.

After the baby is born, parents usually schedule an appointment with one of the specialists at the clinic and see them regularly. Generally, clinics do not provide the daily care that a pediatrician does. Instead, the clinic may serve as a “check point” to present your child’s medical history and developmental progress. From this information and a physical exam as well as an evaluation, the clinic specialist may be able to recommend additional therapies or tests to make sure that your child is receiving all that she needs. These clinics are staffed by physicians who are experts on Down syndrome and have seen many children with the condition. Unlike a pediatrician who might have one or two patients with Down syndrome in their practice, Down Syndrome specialists see many children and therefore know how to identify subtle medical issues.

Clinics vary in the services they provide, but some may be able to refer you to specific specialists or therapists whom you may be able to see on the day of your visit. The clinic may also be able to help you with contacting a local Down syndrome group. NDSS provides a [list of clinics](#) separated by region and state.

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### *Finding a local group*

[Down Syndrome Affiliates in Action Affiliate Directory](#)

[NDSC Directory](#)

[Gifts links](#)

[NDSS Affiliate Locater](#)

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## TURNING TO YOUR LOCAL SUPPORT GROUP

Your health care provider may give you contact information for your local group. If not, an internet search should reveal any groups in your area. Most groups have a website with contact information.

Most groups have a new parent outreach coordinator or similar person, and websites usually provide e-mail addresses or phone numbers for contact. Please do not be shy about suggesting the type of support you need. Investigate or ask if the group has a prenatal support program, and if there is a parent available for one-on-one support. If you prefer to speak to someone who had a prenatal diagnosis, or someone who has faced ancillary issues similar to those diagnosed in your baby (a specific heart defect for example), please ask the contact. He or she will likely be able to send an email to the group seeking out such a person.

Contacting your local group and speaking with a member will also give you an opportunity to learn about the local Early Intervention services, medical facilities, the educational system, social support, and your state's laws and procedures for assistance such as SSI or Medicare.

In addition to one-on-one support, you may wish to attend a general meeting, playgroup, or an adult social event to get acquainted with the community.

If you find that you are not getting the support you need, please reach out to the group leader so that they are aware of this gap in support. Many groups are still in the process of developing prenatal outreach programs, and your feedback can be very useful towards meeting that goal.

On the other hand, many expectant parents are uncomfortable with in-person support during post-diagnosis pregnancy when they may be experiencing emotional volatility. An e-mail explaining that you'd like to learn without a personal meeting may address that concern.

## REACHING OUT TO LOCAL PARENTS

In addition to organized groups, or if your area does not have a local group, you may find it helpful to reach out to local parents on your own. Whether a friend of a friend has a loved one with Down syndrome, a member of your religious or civic organization has a loved one, or you remember a friend from your past who has a relative with Down syndrome, most people in this community are more than happy to talk to a new or expectant parent. You may need to get creative with your efforts if no one comes to mind. You may wish to ask your doctor or genetic counselor for the name of any other patients who have a child with Down syndrome. Another idea is to contact the special education department in your local school, or contact the local EI program to see if they have a way to connect you with other parents.

Many expectant parents find that they have a heightened awareness after diagnosis, seeing people with Down syndrome in numbers they never noticed before. Often, parents wish to approach these strangers, but are uncertain if it is appropriate or unsure of how to do so.

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After your child is born, a good technique is to approach and ask, “Do we have something in common?” Usually a parent will then look up and realize the connection, and a friendship may blossom. During pregnancy, it can be a bit more awkward, but can result in great conversation. Perhaps a gentle statement like the following may be a good introduction: “Excuse me, I was thinking we may have something in common. I’m expecting a baby next month, and she has Down syndrome.”

## TURNING TO ON-LINE SUPPORT

There are a variety of internet support groups where an expectant parent may find support, answers to questions, and hope for the future. The advantage of internet support is that a parent can write out a question or introduction any time of the day or night, and await responses from those who are further along on their journey. In addition, on-line support can provide the opportunity to find people who are experiencing a prenatal diagnosis at the same time. You’re also more likely to find a more diverse collection of women who can relate to your family situation, ethnic background, or specific medical issue. Parents can also view pictures of other children and read stories of challenges, successes, and every day life. Further, expectant parents who are feeling emotionally volatile do not need to worry about their ability to “keep it together” when communicating.

The drawbacks of internet support are security concerns connected to dissemination of information, geographic distances from those giving support, possible lack of knowledge about local information, and the occasional disingenuous participant (otherwise known in internet support as “trolls”). Parents should use the internet as a valuable tool, but exercise caution and good sense. These are the more well-known and/or useful internet support groups:

### *Discussion Groups*

- [\*Down Syndrome Pregnancy Baby Center Forum\*](#)  
Melissa “Missy” Skavlem and Nancy Iannone moderate a discussion board that has offered daily support to parents with a prenatal Down syndrome diagnosis for the past four years.
- [\*Down Syndrome Baby Center Forum\*](#)
- [\*I-Village T-21\*](#)
- [\*CafeMom T21\*](#)
- [\*Uno Mas Down Syndrome Online\*](#)
- [\*DownSyn Forum\*](#)
- [\*Trisomy 21 Online\*](#)

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### *A Word About Language*

Once you become involved in the community, you may notice that the parents of children with Down syndrome use specific language to refer to their children. One common idea is called “People First” language. For parents, that means referring to their child with Down syndrome by saying “my child with Down syndrome” rather than “my Down syndrome child” or “my Down’s child.” The reason behind this is that the language shows that the most important thing about a person with Down syndrome is not her diagnosis but her individuality as a person. Typically, people in the United States use the term, “Down syndrome,” while people in the UK use the term, “Down’s syndrome.”

Also, while some professionals still use the term “mental retardation,” and it is still a proper medical term, many parents and advocates bristle at this description because of the baggage that comes with the words. Some other descriptions you might hear are cognitive disability, cognitive delay, intellectual disability, or developmental disability.

Special Olympics has actually started an *r-word* campaign to raise awareness about the impact of some words.

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## FINDING RESOURCES

When a couple receives a prenatal diagnosis of Down syndrome, they often experience fear and anxiety about the future. Will finding out information about Down syndrome increase this anxiety or comfort parents? Surprisingly, the answer is yes to both.

On one hand, parents may have outdated ideas about Down syndrome based on limited exposure and knowledge. If an expectant parent researches Down syndrome, they will hopefully learn about the advances in medical treatments, increasing social acceptance, leaps in the educational field, studies reflecting healthy family impact, and the current status of promising research on cognition.

However, it is likely expectant parents will also come across a list of issues that are “associated” with Down syndrome, along with quite a bit of outdated or incorrect information as well. This may increase the anxiety a couple faces.

You should first decide how much you want to learn about Down syndrome before you start to research. This booklet gives a general overview on potential issues, with a focus on the newborn period, but we also provide resources so you may obtain more information. The positive side of research is that the more you learn, the better equipped you will be to handle any issues that may occur. Research can help you regain a sense of control over the situation.

The drawback to research is that you may project all of these issues on to your baby, causing unnecessary anxiety since your baby will likely not have

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all, or many, of the issues on a “potential” list. If you decide to learn as much as you can, remember that once the baby is born, you will only have to deal with the issues he or she has, not the list of possibilities.

## NATIONAL DOWN SYNDROME ORGANIZATIONS

There are two national groups which provide information and support to parents, the National Down Syndrome Society (NDSS) and the National Down Syndrome Congress (NDSC). There is also an international group for people with mosaic Down syndrome. Additionally, the Down Syndrome Research and Treatment Foundation (DSRTF) funds modern and very promising research into improving cognition for people with Down syndrome and has very useful information about the status of current research.

- [\*National Down Syndrome Society\*](#)
- [\*National Down Syndrome Congress\*](#)
- [\*International Mosaic Down Syndrome Association\*](#)
- [\*Down Syndrome Research and Treatment Foundation\*](#)

## EXPECTANT PARENT RESOURCES

The following resources have been specifically created for expectant parent support during pregnancy:

- [\*Lettercase.org\*](#)  
“Understanding a Down Syndrome Diagnosis” published by Lettercase is the nationally recommended resource for parents initially receiving a prenatal diagnosis. It features photos of people with Down syndrome in their everyday lives and includes reliable resources and studies about Down syndrome.
- [\*Brighter Tomorrows\*](#)  
Brighter Tomorrows is a website created by the Interdisciplinary Human Development Institute, and it provides a range of resources for expectant parents.
- [\*The Light at the End of the Tunnel\*](#)  
This booklet is full of advice from parents who had a prenatal diagnosis and was produced through a collaboration between NDSC and the Orange County parent support group. Some of the stories are faith-based.

## BOOKS

There are both practical guides and inspirational reading connected with Down syndrome. Try to find literature that is as current as possible, since research and social and educational advancements are constantly changing the landscape for people with Down syndrome. We understand that all the information can be overwhelming, so we’ve included a list of books that other moms have found to be the most helpful:

- [\*Babies with Down Syndrome: A New Parent’s Guide\*](#) by Susan J. Skallerup  
This recently updated book provides a practical guide for infancy.

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- *A Parent's Guide to Down Syndrome: Toward a Brighter Future* by Siegfried M. Pueschel  
This book offers a practical guide for childhood with information about adulthood.
  - *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives* by Kathryn Lynard Soper.  
This is a compilation of stories about the journey from shock to the realization of what our children bring to our lives, including stories from mothers who received a prenatal diagnosis.
  - *Common Threads: Celebrating Life With Down Syndrome* by Cynthia S. Kidder and Brian Skotko  
This book features beautiful pictures and essays.
  - *Road Map to Holland: How I Found My Way Through My Son's First Two Years With Down Syndrome* by Jennifer Graf Groneberg

## DVDS AND ON-LINE VIDEO CLIPS

- *Down Syndrome: The First 18 Months* and other Down syndrome videos
- *A Promising Future Together*  
This NDSS clip is approximately 36 minutes. It is well worth the time, very comprehensive, and presented in a documentary style. There are interviews with new parents as well as parents of adults, and medical professionals. It discusses the shock of diagnosis and moving beyond, newborn screenings, alternative therapies, Early Intervention & development, maximizing potential & expectations, engaging your family/siblings, and looking ahead.
- *The Journey Ahead*  
This 15 minute clip has been produced by the Down Syndrome Association of Greater Cincinnati (DSAGC). It is produced in a comprehensive, documentary style.

## BOOKLETS

- *Expecting an Extraordinary Life: A New Parent's Guide to Down Syndrome*  
The DSAGC's comprehensive booklet for new parents includes stories and covers breastfeeding, medical concerns, etc.
- *What Parents Wish They'd Known: Reflections on Parenting a Child with Down Syndrome* by Kathryn Lynard Soper



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## CONCLUSION

The Down syndrome community has a long tradition of paving the road for those who are behind us in their journey. As prenatal testing becomes more sophisticated, the percentage of parents in the Down syndrome community who have received a prenatal diagnosis will continue to rise. In the near future, virtually all new parents of children with Down syndrome will likely receive a prenatal diagnosis. These expectant parents should receive the understanding and support of this wonderful community.

As you go forward on this path of unexpected adventures, we hope that this book will be a travel guide that you will consult on a regular basis. Although no one can truly know what to expect until they actually experience the journey from diagnosis to delivery, we hope this book will serve as a comforter, checklist, encyclopedia, translator, organizer, and shortcut as you explore this new territory. As we end this book, we know that you are just beginning your journey. In many ways, we are beginning as well as we try to find a new way to support you. If you follow us on the Down syndrome pregnancy website, you will find more resources, and an entire community of people waiting to help you.

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## ABOUT THE CREATORS

*Author Nancy Iannone*



Ann Marie “Nancy” McCrea Iannone graduated with a Bachelor of Arts in English from Rutgers College, Rutgers University in 1989. She received a Juris Doctorate in 1994 from Rutgers University School of Law in Camden, where she graduated with High Honors and Tax Honors with Distinction and served on the editorial board of Rutgers Law Journal. Nancy spent several years practicing law and teaching writing to law school students before retiring after the birth of her second child.

Nancy lives in New Jersey with her husband of 17 years, Vincent, and their four daughters, Samantha, Maria, Elena, and Gabriella. In 2004, Nancy and her husband received the news that their unborn baby Gabriella had both Down syndrome and a heart defect which would require open heart surgery.

“Receiving and adjusting to Gabby’s diagnosis was the single most difficult thing I’ve ever done. There is a feeling of isolation, a self-consciousness not seen since adolescence, fear of the unknown health issues we may face, awkwardness when telling people ‘the news,’ dealing with comments from people. Yet that difficult time is separate from this life, raising an endearing and vivacious child whose curiosity and humor enrich all of our lives.”

Since early 2006, Nancy has been hosting an internet support group for moms with a prenatal diagnosis, and over the years has seen a pattern in the emotional issues, the fears, and the questions of prenatally diagnosed parents. In 2007, Nancy wrote an essay entitled “A Hopeful Future” in Kathryn Lynard Soper’s book *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives*. Nancy is also the newly appointed Outreach Coordinator for her local group, KIIDS (Knowledge and Information about Individuals with Down Syndrome) and the Executive Director of DownSyndromePregnancy.org. Joining forces with Stephanie Meredith has allowed both women to meet a very important goal of helping newly diagnosed expectant parents.

Contact Nancy at [nancy@downsyndromepregnancy.org](mailto:nancy@downsyndromepregnancy.org).

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*Author Stephanie Hall Meredith*



Stephanie Hall Meredith graduated from Brigham Young University with a Bachelor of Arts in English in 1997 and a Master of Arts in English in 1999. She has worked as a technical writer and a science/medical writer for over ten years, worked as an assistant editor for Pat Bauer's disability news blog, and also occasionally teaches English classes at local universities.

Stephanie lives in Canton, Georgia with her husband, Justin, and their three children, Andy, Kate, and Lily Jane. Stephanie's first child, Andy, was born with Down syndrome in January 2000.

"When my husband and I found out that our son Andy was born with Down syndrome 10 years ago, we were devastated 23-year-olds who were terrified about the future ahead of us. At the time, we felt overwhelmed by the news, and I was incredibly depressed that Andy had to stay at the hospital to resolve some medical issues.

The first time we started to glimpse "normal" again was when a mom who provided support at the hospital showed us a photo of her son with Down syndrome on a bike. At that moment, my husband and I both thought that if the little boy in that photo was our future, then we could handle it.

Now, that news has become an ordinary reality. Therapy schedules are simply part of our routine, and we go on vacations, referee sibling squabbles, and ride bikes in the neighborhood just like everyone else. Of course, we work hard to help Andy overcome his challenges, but it's just a part of life. However, I must admit that it has given us a clarity that has forever changed the way we see the world and the people in it."

Stephanie is the author of the booklets, "Delivering a Down Syndrome Diagnosis" and "Understanding a Down Syndrome Diagnosis," which were selected as the national gold standard by the Kennedy Foundation First Call Advisory committee. She also coordinated the translation of *Babies with Down Syndrome* into Russian and is a contributing author with the essay, "Leader of the Pack," in *Gifts 2: How People with Down Syndrome Enrich the World* edited by Kathryn Lynard Soper.

Contact Stephanie at [stephanie@downsyndromepregnancy.org](mailto:stephanie@downsyndromepregnancy.org).

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## Photographer Conny Wenk



Conny Wenk started capturing the beauty and personality of children with Down syndrome after her own child Juliana was born in 2002. Conny's blog and books blend gorgeous photography and personal essays from parents to give the audience an intimate glimpse into the lives of families who have children with Down syndrome. Her shoots are simple – a day in the park, having fun with friends, or even sharing a meal. With these every day settings as background, Conny focuses in on the moments of life that illustrate the joy and excitement in the life of a person with Down syndrome.

"Photography has always been my great passion. But thanks to my wonderful daughter, my passion became my profession. Eight years ago, when Juliana was born and diagnosed with Down syndrome, our world seemed to fall apart. After I recovered from the initial shock, I began to see with new eyes. I became aware that real beauty is much more than meets the eye, and how symmetric the face and body are. It's the inner beauty. Somebody with a beautiful mind and soul is a very beautiful person. And a happy one!"

Conny Wenk has created three books:

- *Schmetterlingszauber*, a celebration of the wonderful friendship of three little girls.
- *Aussergewoehnlich*, about 15 mothers and their children with Down syndrome.
- *Aussergewoehnlich: Vaeterglueck*, about 22 fathers and their children with Down syndrome.

Conny also has a 2010 calendar and a 2011 calendar featuring people with Down syndrome.

For information on Conny's work and to see more gorgeous photography, visit Conny Wenk's blog: [connywenk.com](http://connywenk.com)

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## Photographer Kelle Hampton



Kelle Hampton is a professional photographer whose goal is to capture beauty in its purest form, telling the story of those she photographs, with all of their quirks, their humor, and the spark of their personalities. Kelle has been blogging about her life since the birth of her daughter Lainey in 2007, weaving words and photography together to celebrate the small things in her family life in which she finds so much beauty. In January of 2010, Kelle gave birth to her second daughter and learned that Nella Cordelia has Down syndrome. Her world was “rocked to the core” and she was sure life as she knew it was over. She was wrong – and Nella Cordelia is showing Kelle that life with an extra chromosome is amazing and beautiful, transforming her as a person and revolutionizing her photography.

“Beauty isn’t always where we expect it. And when we truly allow ourselves to look for it and find it, we are changed for good. My goal is to capture images of beauty in its purest form – not in the perfect outfit, the perfect pose, the perfect smile. No, that’s not what you want to remember. You want to remember what you see every day ... real, raw beauty. Life happens everywhere ... and it is beautiful. The true challenge is to bottle it up, and that’s what I do ... with every little click of my shutter.”

Kelle lives in Naples, Florida with her husband Brett, his two boys, Austyn and Brandyn, and their two daughters Lainey and Nella Cordelia.

Kelle Hampton Photography: [kellehamptonphotography.com](http://kellehamptonphotography.com)

Kelle Hampton’s Photography Blog: [kellehampton.blogspot.com](http://kellehampton.blogspot.com)

Kelle Hampton’s Family life Blog, Enjoying the Small Things:  
[kellehampton.com](http://kellehampton.com)

Nella Cordelia’s Birth Story:

[kellehampton.com/2010/01/nella-cordelia-birth-story.html](http://kellehampton.com/2010/01/nella-cordelia-birth-story.html)

In July of 2010, Kelle received a National Down Syndrome Congress Media Award.

