

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

Nancy McCrea Iannone and Stephanie Hall Meredith



DownSyndromePregnancy.org

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

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The information is based on many hours of research, discussions with experts, and 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 time 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. Additionally, anyone found to violate our copyright or modify or alter the images or text of this title, either in print or via virtual sabotage, will be prosecuted to the fullest extent of the law.

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We are not medical professionals. Although we have sought advice from experts, and have provided medical information, this book is meant to be a resource for you to understand this information, research the information yourself, and most importantly provide you with questions and issues for you to discuss with your medical care provider. All decisions about your care should be fully discussed with your medical care provider. This book is not a substitute for good quality medical care and advice.

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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 another booklet which is appropriate for any patient receiving a prenatal diagnosis, including those currently making reproductive decisions, entitled *Understanding a Down Syndrome Diagnosis*. That booklet was created with input by representatives from the American Congress of Obstetricians and Gynecologists, the National Society of Genetic Counselors, the American College of Medical Genetics and Genomics, and the national Down syndrome organizations. Please refer to 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, so that they can access the book and its links, and make full use of our online articles that supplement the information in the book. For quality printed copies of this book, you may order from *Woodbine House*. Please also see the *Checklist for Local Organizations* at DownSyndromePregnancy.org for ideas about what local information, resource lists, web links, and volunteers you might want to have on hand to support expectant parents.

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1. *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives* by Kathryn Lynard Soper
2. *Gifts 2: How People with Down Syndrome Enrich the World* by Kathryn Lynard Soper
3. *What Parents Wish They'd Known: Reflections on Parenting a Child with Down Syndrome* by Kathryn Lynard Soper (free download)
4. *Babies with Down Syndrome: A New Parent's Guide* by Susan J. Skallerup
5. *Gross Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals* by Patricia C. Winders
6. *Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals* by Maryanne Bruni
7. *Early Communication Skills for Children with Down Syndrome, A Guide for Parents and Professionals (2nd ed.)* by Libby Kumin, Ph.D., CCC-SLP
8. *DVD: The First 18 Months* by Will Schermerhorn
9. *Your Loved One Is Having a Baby with Down Syndrome* by Amy Geoffrey, Nancy Iannone, and Stephanie Meredith



WELCOME

Dear Expectant Parents,

If you are opening the pages of this book, you have probably just received the news that your unborn baby likely 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 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 online, 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 develop 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.

Warm Regards,

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 BASICS

Many expectant moms start this journey with some very basic questions. What is Down syndrome? What does my prenatal testing actually mean? Once moms have a basic understanding of the condition, and a clearer picture of the likelihood of their baby having a diagnosis, they are ready for more detailed information. This chapter explains those basics, and how to use this book to gather more information.

UNDERSTANDING THE BASICS ABOUT DOWN SYNDROME

Down syndrome is a genetic condition that is usually caused by an extra copy of the twenty-first chromosome. According to current estimates, about 250,000 people in the US have Down syndrome¹. Studies show that about 1 in 830 babies are born with Down syndrome², and your chances of having a baby with a genetic condition increase with age.

The medical conditions and abilities vary widely; however, people with Down syndrome generally have mild to moderate cognitive delays, low

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- 1 Presson, A.P., Partyka, G., Jensen, K.M., Devine, O.J., Rasmussen, S.A., McCabe, L.L., McCabe, E.R.B. (2013). Current estimate of Down syndrome population prevalence in the United States. *J Pediatr*, 163(4):1163-1168.
 - 2 Shin M., Besser L.M., Kucik J.E., Lu C., Siffle C., Correa A., et al. (2009) Prevalence of Down syndrome among children and adolescents in 10 regions of the United States. *Pediatrics* 124:1565-1571. (Indicative of the live birth numbers from data reported around 2003.)

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 health care, education, and public attitudes.

Health care research and technology have improved drastically over time. Currently, the average life expectancy for people with Down syndrome is about 60.^{3,4}

People with Down syndrome have also 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, create better learning atmospheres. Over 250 college programs for people with intellectual disabilities are also giving more opportunities for independence and growth.

Improved public attitudes and acceptance have also meant that many people with Down syndrome are thriving as active and valued members of the community. This includes children who are increasingly joining social and school programs with their peers, and many adults who 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 first and foremost be a member of your 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 influenced by the genetics and nurturing in your home.

UNDERSTANDING THE BASICS ABOUT PRENATAL SCREENING AND TESTING

You may be reading this book because you have received the news via a diagnostic test — amniocentesis or chorionic villus sampling (CVS) — that your baby has Down syndrome. Because these tests are nearly certain, you are preparing for the reality that your baby has a diagnosis. On the other hand, you may have received the news of a high likelihood of Down syndrome via a non-invasive screening test and wish to prepare for a baby with a diagnosis even though the results are not as certain as an amnio or CVS. However, you may still be wondering exactly what the test results mean for your pregnancy.

The landscape for prenatal screening and testing is constantly changing, and it can be difficult to understand all the different options and results.

3 Glasson, E.J., Sullivan, S.G., Petterson, B.A., Montgomery, P.D., Bittles, A.H. (2002). The changing survival profile of people with Down syndrome: implications for genetic counselling. *Clinical Genetics*, 62:390-393.

4 Wu J., Morris J.K. The population prevalence of Down's syndrome in England and Wales in 2011. (2013). *Eur J Hum Genet*; 21:1016-1019.

Currently, it's most accurate to say that the only way to know with over 99% accuracy that your baby has a diagnosis is to undergo a CVS or an amnio. Traditional screens use blood samples, ultrasounds, and other fetal measurements, to give you your chances for having a baby with Down syndrome as a ratio. These tests should not be considered "positive" or "negative." The newer "non-invasive screening tests" are much more accurate than traditional screening tests and are often delivered as a "positive" or "negative," though false positives and, more rarely, false negatives still occur.⁵ Therefore, they are still considered a screen because they are not definitive. For pregnant moms who choose to undergo testing, you have a number of choices based on your personal preferences, values, insurance coverage, etc. To really understand all the options, it is important to talk to a genetic counselor both before testing and after testing.

You can also read the Lettercase "***Understanding Prenatal Screening and Testing for Chromosome Conditions***" pamphlet for more information about the different kinds of prenatal screening and testing; reasons why pregnant moms might or might not want to undergo testing; and the different conditions for which they are being tested. This pamphlet was created with input from representatives of the National Society of Genetic Counselors.

Ultimately, the decisions about screening, testing, and preparation are entirely up to you and based on your individual preferences. For example, one mom might choose to undergo an amnio after getting a "positive screen result" because she wants to know for certain and so that she can test for additional genetic conditions that can be detected with an amnio. Another mom, for instance, may choose to undergo traditional screening tests and then opt to undergo the newer non-invasive screening test. After receiving a "positive" screen result, she may choose to go ahead and prepare for a baby with Down syndrome. Her reasoning may be that an amnio or CVS carries a slight risk of miscarriage, and she would rather get a possible false positive rather than posing even the slightest risk to her pregnancy. There are many reasons why women choose different testing paths, and their decisions should be based on a thorough knowledge of the available options and the preferences of the family.⁶ It is important to note that medical professionals are increasingly telling their patients that they should not rely exclusively on the non-invasive prenatal screening results if they are making irreversible pregnancy decisions.

5 Gregg A.R., Gross S.J., Best R.G., Monaghan K.J., Bajaj K., Skotko B.G., Thompson, B.H., Watson M.S. (2013). ACMG statement on noninvasive prenatal screening for fetal aneuploidy. *Genet Med* 15:395-398; doi:10.1038/gim.2013.29

6 For a research-based discussion of the complexities involved with prenatal testing decisions after the introduction of NIPT as an option, see: Chetty S., Garabedian M.J., Norton M.E. (2013). Uptake of noninvasive prenatal testing (NIPT) in women following positive aneuploidy screening. *Prenat Diagn* 33(6):542-6; doi:10.1002/pd.4125

USING THIS BOOK

This book gives expectant mothers the essential information they need to know about a pregnancy after learning about a prenatal diagnosis of Down syndrome. 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.

The *DownSyndromePregnancy.org* website also features other helpful booklets, including "Your Loved One Is Having a Baby with Down Syndrome" for family and friends to better understand your experience and how to provide support. The booklet "Coping with Loss" was created for the minority of expectant parents who experience miscarriage, stillbirth, or the loss of a child. The website also features articles that correspond with the book chapters and include links to additional resources and parent stories. We also put updated information in these articles to let you know about anything new.



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MONITORING YOUR PREGNANCY POST-DIAGNOSIS

If the results of prenatal testing reveal that your baby has Down syndrome or a high likelihood of having 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 about 50% 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.⁷

⁷ 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 27 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 diagnosis has been confirmed or if you have a high likelihood of Down syndrome and have made a definite decision to pass on further testing, 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 explain test or screening results; give you more information about Down syndrome; provide the likelihood of recurrence in future pregnancies; and evaluate 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 and Genomics*.

2. **Perinatologist or Maternal Fetal Medicine Specialist.** 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, 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 located in your area. See “Finding a Down Syndrome Clinic” on page 78 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 61 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, if a GI issue is suspected or confirmed. See “Gastrointestinal Issues” on page 60 for more information.
6. **Lactation consultant or similar expert.** If you wish to breast feed your newborn, 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 53 for more information.
7. Other specialists. If other issues develop during your pregnancy, you may be referred to an expert in the appropriate field.

Related Articles on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for articles such as, “*Your Prenatal Care*” and “*Playing the Waiting Game*.”



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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 diagnosis of Down syndrome 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 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. See “Creating and Evaluating Your Birth Plan” on page 49 for more details about how to write a letter addressing any concerns and how to create a plan with your medical provider.

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, some health care providers may behave inappropriately when faced with a patient’s decision to welcome her baby. 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 support 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.

[Related Articles on DownSyndromePregnancy.org:](#)

You can visit [DownSyndromePregnancy.org](#) for articles such as, “***Creating and Evaluating Your Birth Plan.***”

This article includes templates for letters to medical providers that you can copy, paste, and personalize to express your desires and concerns.



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ADJUSTING TO 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, then commonly followed by emotional growth and 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 "blind-sided," "devastated," 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"⁸ that can be remembered with perfect clarity decades later.

8 Skotko, B. (2005). Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics & Gynecology*, 192: 670-677.

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 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 adjustment 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 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 people with disabilities, or slang words for those with intellectual disabilities

These feelings are common for many expectant moms and do not reflect how you will be as a parent or how you will bond with your baby. They are a normal part of the adjustment 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.

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 delivery.⁹ 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.

Recent research also shows that most people with Down syndrome are overwhelmingly valued and loved by their families. So, even though the emotions may swing throughout pregnancy, most families adapt and find joy. Interestingly, the results of this survey did not change based on the abilities of the individuals with Down syndrome — meaning that satisfaction in family relationships did not depend on whether the individuals had significant or mild disabilities.

- 99% of people with Down syndrome said they were happy with their lives
- 97% of people with Down syndrome liked who they are¹⁰
- 99% of parents said they love their child with Down syndrome¹¹
- 97% of brothers/sisters, ages 9-11, said they love their sibling¹²

Related Articles on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for articles such as, ***“The Emotional Impact of Diagnosis;” “Reclaiming Joy;” “Diagnosis Day: Parents, What Would You Say to Your Past Self;” “Who Was I Then? Who Am I Now?;” “50 Things to Do Instead of Worry;”*** and ***“Support for Dads.”***

9 Skotko, B. (2005). Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics & Gynecology*, 192: 670-677.

10 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Self-perceptions from People with Down Syndrome. *American Journal of Medical Genetics, Part A*: 155:2360-2369.

11 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers. *American Journal of Medical Genetics, Part A*: 155:2335-2347.

12 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Having a Brother or Sister with Down Syndrome: Perspectives from Siblings. *American Journal of Medical Genetics, Part A*: 155:2348-2359.

THErapy DURING PREGNANCY

The long months of living with a diagnosis in a vacuum without a baby to hold can be emotionally exhausting. It is very important that you take care of your own emotional well-being, especially if there are other 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.

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 delivery) 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*. You may answer “yes” to many of the questions involving sadness, fear, or stress, because these are natural results of receiving a prenatal diagnosis. For many expectant moms, family support, local Down syndrome groups, or online communities 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. *Postpartum Progress* has online 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 National Suicide Prevention Lifeline* (1-800-273-TALK (8255)).

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 or likelihood that your baby has Down syndrome, your adjustment period may be marked by concerns for your unborn child.

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 15.

ASSESSING THE RISK OF MISCARRIAGE

The actual risk for miscarriage while expecting a baby with Down syndrome is based on many different variables. While the risk for miscarriage is higher when a baby has Down syndrome, this risk is lower for younger mothers. The risk also decreases as the pregnancy progresses. Approximately 68% of pregnancies identified at 10 weeks gestation will result in a live birth, with estimates ranging from 77% for mothers aged 25 to 66% for mothers aged 45. Among pregnancies at 16 weeks gestation, approximately 75% will result

in live births, with estimates ranging from 81% for mothers aged 25 to 67% for mothers aged 45.¹³

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. In addition, the research does not take into account many factors. Advances in prenatal technology and aggressive prenatal monitoring 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 still have 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 most women will continue their pregnancies, 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 DownSyndromePregnancy.org that gives them additional resources, ideas for creating remembrances of their child, and notes from other moms who have experienced the loss of a child with Down syndrome.

13 Savva, G.M., Morris*, J.K., Mutton, D.E., 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

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 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 other issues if any). We learned the results through a genetic test called an amniocentesis/ CVS, which is virtually 100% accurate. Alternatively: We have recently learned that our sweet baby likely has Down syndrome. Though we have decided against having amniocentesis or CVS, the screening tests we have taken have indicated that there is a strong chance

our baby has Down syndrome. Therefore, we are preparing for the likelihood that our baby has a diagnosis.

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 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 for some basic information for friends and family in the booklet, “Your Loved One is Having a Baby with Down Syndrome.” 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 outcomes. 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 sometimes, and it tends to hurt after awhile.

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 opportunities for people with Down syndrome are better than ever, and we are looking forward to the bright future ahead of NAME.

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.

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 or after you’ve processed 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.

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. Email. Social media. 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 email 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 email access, but it is a good tool for letting a large group of people know.

Large social networks, such as Facebook, Instagram, blogs, and Twitter, are also a popular way of sharing updates with family and friends. It may be useful to share the news about your baby on these sites when you want to reach a large group of people at one time or reach people whose contact information is difficult to find. This is often the preferred method when you are ready to let everyone know.

Social media allows you to control the message, but, unlike email, it also leaves you open to immediate reactions from others, who could be wonderful or, occasionally, thoughtless. For this reason, most expectant parents find social media to be a better second or third tier method of making an announcement, after they have already told close friends and family and have had time to adjust to the diagnosis. Fortunately, our social media friends usually follow our cues. So, if you share the diagnosis with a positive perspective, then most comments will likely reflect your tone and be a genuine source of strength and support so that everyone celebrates when your little one arrives.

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.

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.

[Related Articles on DownSyndromePregnancy.org:](#)

You can visit DownSyndromePregnancy.org for articles such as, ***"Telling the News"*** and ***"Positive Support from Family and Friends: Saying Thank You."***

Both articles include templates for emails that you can copy, paste, and personalize to tell the news to friends and family and express thanks.



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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' feel-

ings 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” 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 the use of 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've made 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. 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 the pointed, "Did you mean to say that out loud?" Other responses 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 thinking before you speak?*

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.

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 a diagnosis 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 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 a diagnosis make us fear you will not."*

Alternatively, if you have high chances via NIPS/NIPT and you have chosen to prepare for the baby having Down syndrome: "Thank you for thinking of me. We are actually moving forward and preparing to welcome a baby with Down syndrome. We have had a new test that is much more accurate than the old screening tests. And, yes, we know there is a possibility that the baby does not have a diagnosis, but we have decided to focus on the joy we could have raising a child with Down syndrome."

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.*

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 it's "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 stripped 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 emotions are 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 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 samples 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.”*

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 a diagnosis?*

“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. You either have it or you don’t.¹⁴ We’ll just have to wait and see about the medical issues. As far as cognitive ability, there is a wide variation, 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.”*

14 Not applicable for children with Mosaic Down syndrome. This diagnosis could require a more complicated answer. Please refer to imdsa.org for more information.

Unspoken answer: *I can't believe people expect me to know the answer to this question. He's not even born yet! Can anyone tell how their child will turn out or how smart they will be during pregnancy? I know this is a version of being supportive, but it makes me feel "put on the spot" while I'm still learning about the possibilities for this baby. 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 underlined. 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.

[Related Articles on DownSyndromePregnancy.org:](#)

You can visit [DownSyndromePregnancy.org](#) for articles such as, "***Dealing with People and Comments.***"

This article also includes templates for emails you can copy and paste to gently ask friends and family to use kinder words and avoid offensive slang.



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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 other siblings 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.¹⁵

Research also shows that the siblings of children with Down syndrome tend to be more compassionate and well-adjusted.¹⁶ Another study showed that siblings 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.¹⁷

Dr. Brian Skotko, a notable researcher who has a sister with Down syndrome, conducted a survey of 822 siblings across the country to find out what they

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- 15 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.
 - 16 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.
 - 17 Cuskelly M., Gunn P. (2007). Adjustment of children who have a sibling with Down syndrome: perspectives of mothers, fathers and children. *Journal of Intellectual Disability Research*, 50(12):917-925.

thought of their brother or sister with Down syndrome, and he learned the following:

- More than 96% of them said they felt affection toward their sibling with Down syndrome.
- 94% of older siblings said they were proud of their loved one with Down syndrome.
- 88% of those older brothers and sisters also said they were better people because of their brother or sister.
- More than 90% planned to remain involved in their sibling's lives as they grew older.
- Less than 10% of siblings felt embarrassed by their brother or sister with Down syndrome.
- Less than 5% said they'd like to trade their sibling.

Dr. Skotko often jokes that it would be interesting to compare how many siblings would like to trade their brother or sister who doesn't have Down syndrome. Overall, the study shows that the vast majority of siblings have positive and rewarding relationships with their brother or sister with Down syndrome.¹⁸

Some parents also express concern about the impact of a child with a diagnosis on their marriage and the possible ways marital problems might affect the other children. The good news is that one study shows that the overall divorce rate is actually lower for the parents of children with Down syndrome.¹⁹

Even though a child 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 five 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; they might reveal the information in steps by explaining that the baby is going to need extra help learning to walk or talk;

18 Skotko, B.G., Levine, S.P., Goldstein, R. (2011). Having a Brother or Sister with Down Syndrome: Perspectives from Siblings. *American Journal of Medical Genetics Part A*, 155:2348-2359.

19 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.

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. Dr. Brian Skotko says that “many parents find it helpful to read the children’s books from Woodbine House which contain characters who have Down syndrome. At first, reading the story without drawing attention to the fact that the child has Down syndrome is helpful at reading time. Then, as the book becomes a favorite, the parents can point out that one character has Down syndrome, which can be a nice way to introduce the topic to young siblings.”

Elementary school-aged children can typically understand 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 the genetics when a person has an extra chromosome that 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?
- How should I present the information in order 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?

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 a 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 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

Films:

- *Deedah*
A short film narrated by 7-year-old Charlotte May about her brother Jonathon, who has Down syndrome and calls her "Deedah." Charlotte forthrightly answers questions about Jonathon, including love, bullying, uniqueness, delays, and humor. It may be a useful way to illustrate the future for your other children.
- *Brian Skotko and Sue Levine's Down Syndrome Sibling Book: YouTube Channel*
Covers a range of different topics, such as speaking up for your sibling, finding private time, coping if a sibling is embarrassing, and more.
- *Just Like You: Down Syndrome*
This film explains Down syndrome and answers many frequently asked questions from the perspective of teens with the condition and their friends. This film is particularly helpful for adolescents and young adults who want to know how to build relationships with a peer who has Down syndrome.

Conferences and workshops:

Each year the national **NDSC Conference** offers a Brothers and Sisters Conference for siblings who are school-age, currently fourth grade and up. 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 support organization for more information.

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 support organization or in your community. Sometimes it can help your children to meet other siblings so they can see other families like theirs and realize they are not alone.

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. Many expectant parents have heightened concerns about their chances of having another baby with Down syndrome, but those fears often fade over time as they get to know their child. In addition, those parents who have multiple children usually find that the siblings have the same meaningful and close relationships — no matter whether the child with Down syndrome is older or younger than the other children.

Related Articles on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for articles such as, *“Twins;” “Siblings Speak Out: Jenni Newbury;” “Sibling Perspectives on Down Syndrome;”* and *“Siblings Speak Out: Jennifer Meyers Bekins, MS, CCC-SLP.”*



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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 delivery. 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 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.

Birthing 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 delivery. 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 my 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 delivery. 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.²⁰

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 delivery?

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.

20 Simpson, J. M. (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*.

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 he or 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 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 as discussed in “Gaining Perspective on Pregnancy Concerns” on page 27. 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.

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,²¹ children with the condition do have 1 in 100 odds for developing leukemia.²²

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. However, banking the cord blood from your pregnancies with siblings could be beneficial to your child with Down syndrome if he or she develops leukemia, which occurs in less than 1% of these children.

If you wish to bank your baby's cord blood for other purposes that could benefit your baby, you might want to discuss any potential benefits with your medical care provider.

In addition, you may wish to consider the possibility of banking your baby's cord blood for later use in research which may benefit the Down syndrome population. Researchers have made great strides in discovering the biological causes for some of the issues associated with Down syndrome. Biobanks will be an important part of future research, and cord blood can be a good source for tissue samples.

To learn about Down syndrome research, contact a reputable research organization such as the *Lumind Foundation* or *Research Down Syndrome*.

Related Articles on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for articles such as, "**Organization and Preparedness 101**" and "**Creating and Evaluating Your Birth Plan.**"

This article also includes templates for letters to medical providers that you can copy, paste, and personalize to express your desires and concerns.

21 Satgé D., Bénard J. (2008). Carcinogenesis in Down syndrome: what can be learned from trisomy 21? *Semin Cancer Biol*;18(5):365-371. Epub 2008 Apr 1.

22 <http://www.dsmig.org.uk/library/articles/cards-leukaemia-2.pdf>



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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 breastfeed with no problems. However, others have difficulty due to a weak suck, sleepiness, tongue thrust, or other medical issues such as 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 someone during your pregnancy 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 to discuss potential issues and solutions and to develop 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.

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

- *Canadian Down Syndrome Society: Breastfeeding a Baby with Down Syndrome*
- *La Leche League*
- *Kellymom links to various print and online resources*
- *Children's Hospitals and Clinics of Minnesota: Breastfeeding an Infant with Down Syndrome*

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 72. For more information about infant massage, this *Parenthood article* gives you the basics and resources for more details.

Related Articles on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for articles such as, "***Breastfeeding.***"

This article lists more breastfeeding resources and includes the personal breastfeeding stories of many mothers.



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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 health care have improved so significantly for these medical conditions that the average life expectancy for people with Down syndrome has almost doubled in the past few decades.²³

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.

23 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.

In addition, your health care provider will likely note any physical characteristics of Down syndrome, including eye shape and epicanthal folds under the eyes, the shape and set of the ears, the nasal bridge and shape of the nose, tongue thrust, thickness on the back of the neck, any palmar 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 NICU. 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, such as 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. The American Academy of Pediatrics guidelines for the *“Health Supervision of Children with Down Syndrome”* detail conditions and percentages of the population impacted,²⁴ but we will discuss only some of them based on percentage and newborn status:

Hearing issues (approximately 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 50% 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.²⁵ See “Heart Defects” on page 61 for more details.

Thyroid issues (about 4-18% 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 “Gastrointestinal Issues” on page 60 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

24 American Academy of Pediatrics. (2011). Health Supervision for Children with Down Syndrome. *Pediatrics*, 128 (2):393.

25 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>).

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 53 and ask to meet with an experienced lactation consultant or other expert.

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, please investigate these resources:

Gastrostomy tube

- *Medical University of South Carolina: Tip sheet*
- *Cincinnati Children’s Hospital: Home Care with video*
- *Children’s Hospital of Philadelphia: Questions and Answers*

Nasogastric tube

- *Children’s Hospital of Philadelphia: Questions and Answers*
- *Cincinnati Children’s Hospital: Home Care*

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. 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 up, 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. 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 in your baby's bottle or a suppository 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*.

*More Complex Issues*²⁶

Some babies with Down syndrome experience more significant gastrointestinal issues, such as Hirschsprung disease or duodenal atresia. 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. 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 and 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 DEFECTS²⁷

It is estimated that 50% 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

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

27 See the Cardiology/ Down syndrome website at Cincinnati Children's Hospital (<http://www.cincinnatichildrens.org/patients/child/encyclopedia/default/>); 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>)

delivery. 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.

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.

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. If a child has more complex health issues, you might choose to seek out additional consultation at a nationally-recognized children's hospital. A larger hospital may have more experience with complex issues, so it could be helpful to get further input.

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*
- *Down's Heart Group [UK]*
- *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 delivery 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 online. 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 or **SignUpGenius.com** are other helpful online resources to explore if you anticipate needing meals or childcare during the hospital stay. This website allows volunteers to sign up on a closed community calendar and receive email 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 online support
 - any necessary chargers for your technology devices
4. 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 53.
 - 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 staff if necessary.
 - Ask about breastfeeding policies with babies in the hospital.
5. 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.

6. 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.
- 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*, including a health care checklist at each age
- *Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis of Down Syndrome: Recommendations of the National Society of Genetic Counselors*
- *NDSS Health Care Associated Conditions*
- *Medical and Surgical Care for Babies with Down Syndrome* by Philip Mattheis, M.D. and Susan Eberly
- *“Tracking Your Baby’s Growth and Development”* article at DownSyndromePregnancy.org

As you prepare to welcome your baby, it may also be useful to start a binder or digital file for medical information, where you can keep important records, test results, and questions for your pediatrician and print out the AAP health care guidelines with the Appendix 1 checklist for medical recommendations at each age.

For more information on developmental milestones beyond just health issues, see “What Kind of Developmental Progress Can I Expect My Baby to Make?” on page 71.

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 points are that your child is an individual and that most of these issues, while challenging, are also treatable.

Related Articles on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for articles such as, *“Preparing for a Possible NICU Stay;” “Organization and Preparedness 101;” “Tracking Your Baby’s Growth and Development;”* and *“Calling All Heart Moms.”*



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FINDING SERVICES AND UNDERSTANDING DEVELOPMENT

After receiving a prenatal diagnosis, many parents start to wonder about the nuts and bolts of providing for their child. 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. Others 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.

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.

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 your child — 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. Health care plans under the Affordable Care Act are prevented from denying policies to individuals with any pre-existing condition. Moreover, the cost of the policy is not impacted by the condition but is determined by the level of coverage, the deductible, and demographics, such as location and age. Moreover, you can select these individual policies under the Affordable Care Act from a menu of participating insurance providers, such as Blue Cross or Humana.

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), 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 Supplemental Security Income (SSI), but other times states will require that you apply separately.

If you do not qualify for 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 lim-

ited number of slots available for those programs, and you may be placed on a waiting list.

For a general overview, see *Social Security Online: Benefits for Children with Disabilities*.

HOW DO I SUPPORT A CHILD WITH DOWN SYNDROME?

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 a diagnosis). 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 EI 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 find a list of many early intervention programs at the **Center for Parent Information and Resources' Library** by looking up the Parent Center in your state and exploring the resources or services. 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. Parents report different “start” times for EI that will depend on various 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 children 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. 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)**.

Your role: As the parent, your role in your child's development is central. Specialist therapy can support you and your child by providing expert guidance and modelling effective approaches. Your child's development, however, depends on everyday interactions, play, and opportunities for learning – not just the support your child receives during therapy sessions. You should aim to maintain a positive, collaborative partnership with therapists, observing modeled therapies, 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 also participate in the meetings where the team records progress and sets new goals.

WHAT KIND OF DEVELOPMENTAL PROGRESS CAN I EXPECT MY BABY TO MAKE?

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 in the same order as other children, but it generally takes longer. You can view the *Motor Development & Self-Help Skills Milestones chart* to see the average age when children with Down syndrome accomplish their developmental milestones. Another resource is the *Down Syndrome Developmental Charts* from Down Syndrome Education Online, which includes an overview of the development of babies and infants from birth to five years by Sue Buckley and Ben Sacks.

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.

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 (ST): Supporting the development of listening and speech production skills from early babble to whole words, and the development of clear speech, vocabulary, and grammar.

Sign language teacher: Teaching children and families some sign language or gestures. Children with Down syndrome typically understand – and wish to express more – than they can easily say. Sign language can facilitate communication for children while their speech develops. Some children may require little use of sign language, while others may experience more delay and find more extensive use of sign language useful.

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 basic sign language or gestures appropriate for a toddler. All therapists have a basic understanding of issues with muscle tone, motor planning, and cognition.

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 interaction 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 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 EDUCATION AND LEARNING

In general, many young people with Down syndrome today are achieving more at school and in the workplace than ever before. Outcomes for people with Down syndrome vary widely. Educational expert, Frank Buckley, explains that almost all people with Down syndrome have mild to moderate intellectual disabilities that cause significant learning difficulties and some (perhaps 10%-15%) experience more complex behavioral and cognitive challenges.

Changing social attitudes have reduced isolation, improved services, and offered more stimulating and richer opportunities to young people with Down syndrome. Over the past 40 years, cognitive and educational research has identified many of the specific difficulties experienced by children with the condition. This is informing more effective early intervention and education and helping young people with Down syndrome achieve better reading, speech and math skills and to participate more fully in school and in their communities.

Down Syndrome Education International and their partner Down Syndrome Education USA offer evidence-based resources and services to support families and educators. They also offer learning, communication, and education resources specifically for children ages birth to 5. See their web sites for further information and contact details.

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.

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 away, 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) to a young child.
- ***See and Learn Kits***
Materials aimed at teaching young children with Down syndrome speech, reading, and cognition skills, including learning apps.

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

[*Related Articles on DownSyndromePregnancy.org:*](#)

You can visit DownSyndromePregnancy.org for articles such as, “***Learn to Teach Your Baby.***”



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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, online communities, or other parents to assist you through this adjustment period and prepare you to welcome your child. For many parents, they may turn to online resources or communities right away but may wait to meet in person until a later stage or after the baby is born. Other parents may crave a connection with experienced parents right away. 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 they are worried about the possibility of an emotional reaction in front of other parents. They may feel that their discomfort or sorrow will offend other parents.

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

FINDING GENETIC COUNSELORS AND GENETICISTS

A genetic counselor or geneticist is trained to offer you a more comprehensive explanation of Down syndrome after you receive a confirmed or suspected diagnosis. Even though your health care provider likely has a

basic medical knowledge of the condition, a knowledgeable genetic counselor will be able to provide a broader view about life with Down syndrome, including detailed information about services, modern advances, local resources, 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 while you are pregnant, you may wish to contact them for an appointment.

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, these specialists see many children and know how to identify subtle medical issues.

Clinics vary in the services they provide, but at some clinics, you may be able to see different specialists or therapists on the day of your visit. The clinic may also be able to help you with contacting a local support group. NDSS provides a *list of clinics* separated by region and state.

FINDING 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 email addresses or phone numbers for contact. You can also 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 issues similar to those diagnosed in your baby (a specific heart defect for example), please ask the contact for a referral.

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 Medicaid.

In addition to one-on-one support, you may wish to attend a support group’s meeting, playgroup, or a social event to meet other parents.

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 email explaining that you'd like to learn without a personal meeting may address that concern.

Finding a local group

Gifts links

NDSS Affiliate Locater

REACHING OUT TO LOCAL PARENTS

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 the condition, most people in this community are more than happy to talk to a new or expectant parent. 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.

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."

FINDING ONLINE SUPPORT

There are a variety of internet support groups and blogs 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, online 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 spe-

cific 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. 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 Baby Center Forum***
- ***Down Syndrome Pregnancy Baby Center Forum***
Missy Skavlem, Nancy Iannone, and other volunteers moderate a discussion board that has offered daily support to parents with a prenatal Down syndrome diagnosis since 2006.
- ***Down Syndrome Diagnosis Network (DSDN)***
This network offers Facebook peer-to-peer support organized into birth club years.
- ***International Down Syndrome Coalition (IDSC)***

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.” The reason behind this is that the language shows that the most important thing about a person 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,” many parents and advocates bristle at this description because of the baggage that comes with the words. Some other descriptions you might hear are intellectual disability or developmental disability.

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

Related Articles on DownSyndromePregnancy.org:

You can visit DownSyndromePregnancy.org for articles such as, “***Dealing with Comments (Includes Sample Letter)***,” “***15 Reasons to Reach Out to Your Local Group***,” and “***Online Communities***.”



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FINDING RESOURCES

When a couple receives a prenatal diagnosis, 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 the condition, they will hopefully learn about the advances in medical care, 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 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 SUPPORT ORGANIZATIONS

There are three national groups which provide information and support to parents, the National Down Syndrome Society (NDSS), the National Down Syndrome Congress (NDSC), and Down Syndrome Education USA (DSE USA). There is also an international group for people with mosaic Down syndrome.

- *National Down Syndrome Society*
- *National Down Syndrome Congress*
- *Down Syndrome Education USA*
- *International Mosaic Down Syndrome Association*

NATIONAL DOWN SYNDROME RESEARCH ORGANIZATIONS

The LuMind Foundation, the Jerome Lejeune Foundation, Down Syndrome Education USA, and Research Down Syndrome engage in modern and very promising research into improving outcomes for people with Down syndrome and have very useful information about the status of current research.

- *Lumind Foundation*
- *Research Down Syndrome*
- *Down Syndrome Education USA*
- *Jerome Lejeune Foundation USA*

If you are interested in being invited to participate in research opportunities, staying up-to-date on research initiatives, and being included in the collection of data about Down syndrome, including providing health/medical and demographic information, you might also consider registering for *DS-Connect* sponsored by The National Institutes of Health (NIH).

There are no costs to join, and the information is stored in a secure NIH database. Participation is completely voluntary, and you can request to be removed from the registry at any time. If you have any questions, please contact the registry coordinators at: DSCconnect@nih.gov.

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 the condition.

- ***Brighter Tomorrows***

Brighter Tomorrows is a website created by the Interdisciplinary Human Development Institute, and it provides a range of resources for new and 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.

- ***National Down Syndrome Adoption Network***

For families considering an adoption plan, this organization offers resources about the adoption of children with Down syndrome and has a registry of parents specifically interested in adopting children with a diagnosis.

BOOKS

There are both practical guides and inspirational materials you can read. Try to find literature that is as current as possible, since research, 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 more recent books that other moms have found to be helpful.

Parenting Books

- ***Babies with Down Syndrome: A New Parent's Guide*** by Susan J. Skallerup
This book provides a practical and comprehensive guide for infancy.
- ***Down Syndrome 101*** by Natalie Hale
This book provides organized advice, personal reflections, and explanations to educate parents on a variety of topics, including handling behaviors, teaching reading, interacting with medical professionals, coping with the school system, and more.
- ***Welcoming a Baby with Down Syndrome: A New Mother's Guide*** by Nancy McCreannone and Stephanie Meredith
This book is for mothers whose baby has just been born with Down syndrome and provides an overview of information for the first month of life.

Compilations

- ***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.
- ***Gifts 2: How People with Down Syndrome Enrich the World*** by Kathryn Lynard Soper
This is a compilation of essays from friends and family members about their experiences with their loved one with Down syndrome covering a range of different ages.
- ***Unexpected***
This book offers a range of candid diagnosis stories as told by families whose babies were diagnosed with Down syndrome prenatally or postnatally.

Memoirs

- ***Road Map to Holland: How I Found My Way Through My Son's First Two Years With Down Syndrome*** by Jennifer Graf Groneberg
Jennifer Graf Gronenberg describes the first two years of adjusting to a diagnosis after learning that one of her twin boys was born with Down syndrome and her search to find balance and supportive relationships.
- ***The Shape of the Eye*** by George Estreich
This book, written by a poet whose daughter has Down syndrome, describes raising his child, including processing the diagnosis and dealing with the medical complications of a feeding tube, and also looks analytically at social attitudes towards disability, preconceived notions, and the concept of family.
- ***A Good and Perfect Gift: Faith, Expectations, and a Little Girl Named Penny*** by Amy Julia Becker
Amy Julia Becker shares the deepest thoughts from her personal journal to give an honest and self-reflective account of her reaction to her daughter's diagnosis. The book illustrates the self-awareness she develops as she evolves to embrace the individuality of her daughter with Down syndrome and reconciles the circumstances in her life with her Christian faith.
- ***Bloom*** by Kelle Hampton
Kelle Hampton, who contributed photography to this book, writes about her grief following her daughter's diagnosis and how that grief becomes eclipsed by embracing life and enjoying Nella's first year. Includes full color photography.
- ***Raising Henry: A Memoir of Motherhood, Disability, and Discovery*** by Rachel Adams
Rachel Adams, a professor at Columbia University living in Manhattan, talks about the birth of her son Henry with humor and candor and tackles more complicated discussions about prenatal testing, social prejudice, medical training, and more.

FILMS AND ONLINE VIDEO CLIPS

- ***Down Syndrome: The First 18 Months*** by Blueberry Shoes Production and other Down syndrome videos
This film offers an introduction to the unique joys and challenges faced by parents of children with Down syndrome in the first couple of years and includes footage of children and interviews with parents.
- ***A Promising Future Together***
This NDSS video 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 video clip produced by the Down Syndrome Association of Greater Cincinnati (DSAGC) is produced in a comprehensive, documentary style.
- ***DSACT Down Syndrome in the 21st Century***
This short video created by the Down Syndrome Association of Central Texas for new parents shows an updated outlook for children with Down syndrome and highlights their interests, including signing, swimming, dancing, holding a job, playing with siblings, and public speaking.
- ***Dear Future Mom by CoorDown***
This short international video by CoorDown is a video from people with Down syndrome with a message to new moms about their lives with Down syndrome and their relationships with their moms.

BOOKLETS

- ***Your Loved One Is Having a Baby with Down Syndrome***
This booklet is for friends and family members whose loved ones are expecting a baby with Down syndrome. It gives them an overview of the condition and how they can best support you and know what to say.
- ***Coping with Loss***
This booklet is for women who have experienced a miscarriage or infant loss. This is specifically to help them find resources and support during what can be a very difficult time.
- ***The Congratulations Project***
This is a collection of letters written by adults with Down syndrome to new members of the Down syndrome community. These letters are intended to inspire, encourage, welcome, and congratulate new parents and siblings of a child with Down syndrome.
- ***What Parents Wish They'd Known: Reflections on Parenting a Child with Down Syndrome***
by Kathryn Lynard Soper
- ***A Promising Future Together***
by NDSS



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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 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. 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.

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 is now a writer, a tutor, and a part-time lecturer at Rutgers University School of Law in Camden.

Nancy lives in New Jersey with her husband, 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 Prenatal Outreach Coordinator for her local group, Knowledge and Information about Individuals with Down Syndrome (KIIDS). In 2010, she joined forces with Stephanie Meredith to create the first edition of this book. In 2012, she co-authored the booklet, “Your Loved One is Having a Baby with Down Syndrome,” and in 2014, she co-authored the booklet, “Coping with Loss.”

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 and currently works as the Medical Outreach Director at the University of Kentucky's Human Development Institute.

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, we were 23-year-olds who were scared about the future ahead of us. At the time, we felt overwhelmed by the news, and I was very 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 nationally-recognized booklets, "Delivering a Down Syndrome Diagnosis," "Understanding a Down Syndrome Diagnosis," and "Understanding Prenatal Screening and Testing for Chromosome Conditions, and the co-author of "Your Loves One Is Having a Baby with Down Syndrome" and "Coping with Loss." 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.meredith@uky.edu.

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.

"Photography has always been my great passion. But thanks to my wonderful daughter, my passion became my profession. 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 five books:

- *Aussergewoehnlich* (2004 and a new version 2013): about 15 mothers and their kids with down-syndrome
- *Schmetterlingszauber*: a celebration of the wonderful friendship of three little girls
- *Aussergewoehnlich: Väterglück*: 22 fathers and their kids with Down syndrome
- *Freundschaft* (Friendship): about young adults with Down syndrome and the bond between friends.
- Since 2010 Conny has annually published her wall calender, "A little extra," featuring people with Down syndrome.

For information and to see more photography, visit Conny's websites:

connywenk.com

www.alittleextra.de

www.thegirlwiththefreckles.com

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 Brandy, their two daughters Lainey and Nella Cordelia, and their son, Dash.

Kelle Hampton Photography

Kelle Hampton’s Photography Blog

Kelle Hampton’s Family life Blog, Enjoying the Small Things

Nella Cordelia’s Birth Story

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

“This publication goes beyond just being a very useful resource for couples; it also has a very human side that comes through openly and compassionately. This book points out many important thoughts that I express to my patients ... The more information that a couple has, the better prepared they are to make it comfortable and enjoyable for their family.”

– *Dr. Harish Sehdev, MD, Perinatologist and Director of the Prenatal Diagnosis Unit at Pennsylvania Hospital*

“*Diagnosis to Delivery* takes the mystery out of expecting a child with Down syndrome. This book is an essential guide for any mother continuing a pregnancy after receiving a prenatal diagnosis of Down syndrome.”

– *Dr. Brian Skotko, Physician and Co-Director of the Massachusetts General Hospital Down Syndrome Clinic*

“I wish this resource had been available when my son, Thomas, arrived. It provides exactly what I wished for but could not find: informed, practical, and compassionate guidance in vital matters regarding the well-being of a family newly touched by Down syndrome. With warmth and knowledge born of experience, the authors shed light into the shadowy time when the difficulties of parenting a child with special needs loom large, and the rewards have not yet been discovered.”

– *Kathryn Lynard Soper, Editor of “Gifts, Mothers Reflect on How Children with Down Syndrome Enrich Their Lives,” “Gifts 2,” and author of “The Year My Son and I Were Born”*

“This book hit on every aspect/question that I had concerning the time period from diagnosis to my delivery of my little one. It provided great insight into how I have felt over the last 6 weeks and helped me to know that I am not alone in my feelings, and I thought some of the suggestions for ‘difficult people/reactions’ were priceless.”

– *Sherry Stenehjem, expecting baby boy with confirmed diagnosis of Down syndrome and suspected heart defect*

