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Congratulations!

You have just given birth to a bundle of joy that can give you the joy and the satisfaction you imagined your baby would bring. You have been given the privilege of caring for a child with special needs that other children may not have. Never before have parents of babies with Down syndrome been so prepared to deal with these needs and had so many resources.

We are rapidly learning that our children more alike than different from others; and given the same love, care and environment and learning experiences, can realize their full potential.

There are programs aimed at developing physical and cognitive growth beginning at birth which will help you and your child. These programs and your love, combined with early identification and treatment of any health problems, are the best hope for our children's future.

Right now you may be full of fears, doubts or even bitterness; but your feelings will change after you get to know your newborn. You are not alone. We know and we understand. We have been where you are. This is not the end of the world … only a different kind of beginning.

Mission

Down Syndrome Association of Central Florida (DSACF) was founded in 1991 to enlighten and encourage new parents of children with Down syndrome, as well as to educate the community.

The Down Syndrome Association of Central Florida is an accredited and award-winning not-for-profit association founded in 1991 by parents of children with Down syndrome. It has grown from a few families to over 1,200 individuals with DS and their families. We serve families in an area of over 10 counties with help from more than 17,000 friends, professionals, volunteers and other supporters. We are governed by a volunteer board of directors. More than 50% of our board members have family members with Down syndrome.

DSACF is the leading voice for all individuals with Down syndrome and their families. We offer hope, encouragement and acceptance through advocacy, education and awareness as we guide individuals with Down syndrome through life’s transitions. Together, we create a Central Florida community composed of and dedicated to individuals with Down syndrome – and those who love them – so that each may realize their potential.
2. A Baby is a Baby First

Kate Sefton, Master Developmental Therapist

There is nothing like a baby ... there's a lurch in the heart when we touch the beginning of a life in the small person of an infant. For some parents, the lurch is made more poignant, even painful, by their baby's diagnosis of Down syndrome.

Recently, I have had the great pleasure of holding a number of soft, beautiful babies who have Down syndrome. Their parents want to find out what it all means, what they can do, what to think about the future. The first professionals to talk to the parents of babies with Down syndrome tend to discuss the differences parents may see, difficulties babies will encounter. Armed with information about what milestones their child may not reach, what problems he/she may have, what services they should obtain to avoid potential problems, new parents want to help their babies as soon as possible. So they come to me (and numerous others) to get this help ... to find therapy, activities and solutions to problems that may or may not exist.

We just don't know, at an early age, which ways Down syndrome may affect a child. She may be really good at cognitive activities, but have significant delays in movement ... thereby falling behind her peers in playground and paper and pencil activities. He may be fairly good at gross motor, excelling at sports. Ocular control may be an area of need ... or may be perfect. Language may be good or may need lots of work. However, one thing we know for certain: babies don't deal with these things, no matter what the chromosomes look like. They lie down and expect to be carried, cuddled, talked to, fed and generally catered to. They teach us they are lovable, cute and the center of the universe. They begin to know who their family members are, and who the soft touch in the house in the middle of the night is.

If these adorable creatures have Down syndrome, they are at risk for certain physical and cognitive delays. It behooves parents to keep an eye open for problems that could arise. It's important that they know something about their child's diagnosis so that they can be alert and helpful. But my belief is that the most important thing that parents with babies with Down syndrome can do is exactly those things that all parents do. You know; they cuddle, feed, sing and love. Not the kinds of things you need a developmental therapist for... or any other therapist, for that matter.

I want to be clear. Young children with Down syndrome often show delays that need to be remedied so that these kids can be happy with themselves and do their best. Very young babies with Down syndrome have specific concerns about early development. And doubtless, parents will find themselves driving this child about for ear infections, speech therapy, developmental evaluations, etc. But, the main advice I have for parents of new babies with Down syndrome boils down to this:

You have a beautiful new baby.

There will be some areas that need work, but what you have right now IS PRECIOUS AND PERFECTLY RIGHT.
3. Welcome to Holland

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Frequently Asked Questions

Q. What is Down syndrome?
A. Down syndrome is a genetic variation that occurs when a person has an extra copy of the twenty-first chromosome. This genetic condition may impact a child’s health and development. Children with Down syndrome are at increased risk for heart defects, problems with hearing and vision, frequent infections and developmental delays. One in every 691 babies is born with Down syndrome.

Q. What can cause Down syndrome?
A. An extra chromosome number 21 generally causes it. It is not known what causes the extra 21st chromosome, but it does cause an extra dose of some proteins. Those proteins cause the typical features of Down syndrome. About 95% of people with Down syndrome have Trisomy 21 (literally meaning “3 copies of chromosome 21”). In Trisomy 21, or nondisjunction, the 21st chromosome pair does not split and a double dose goes to the egg (or sperm).

Q. Does the use of drugs or alcohol in a parent before or during pregnancy cause children to have Down syndrome?
A. No. Down syndrome occurs at conception, so nothing in the pregnancy can cause Down syndrome to occur. As far prior to conception, the research all shows that drug or alcohol use does not increase the risk of having a child with DS.

Q. Where did the name Down syndrome come from?
A. Children with Down syndrome are seen in pictures as far back as 1505. However, the first person to clinically identify the condition was a British doctor named John Langdon Down in 1866. Though the term has nothing to do with the physical direction down, Ann Forts, an advocate and motivational speaker who has Down syndrome, has coined the term “Up Syndrome” to provide a different perspective on the condition.
Q. What are the chances that a couple will have a child with Down syndrome?
A. In usual circumstances, the chances depend upon the age of the mother. The odds of having a child with Down syndrome at age 35 are approximately 1 in 400. Under 25, the odds are about 1 in 1250 and at age 40 the odds are about 1 in 100. More than 80% of babies with Down syndrome are born to women under 35.

Q. If maternal age over 35 years is a risk factor for having babies with DS, why are more than half of all babies with DS born to women under 35 years?
A. While it is much more common for babies with DS to be born to women over 35 years of age, women under 35 have a higher birth rate. No risk factors have been found yet for women less than 35 years of age, but several research groups are looking at this question.

Q. What about my child’s health?
A. Children with Down syndrome are at increased risk for a number of health issues, but some have few if any concerns. Gather information from your baby’s pediatrician about any health concerns and make sure to get all of your questions answered. Good medical care will help ensure that your baby stays happy and healthy. The Journal of Pediatrics has specific healthcare guidelines for children with Down syndrome.

Q. How will I afford to care for my child?
A. We all know that kids are expensive and many think that raising a child with Down syndrome is even more costly. In actuality we have found that the costs of raising a child with Down syndrome are not much more than raising one without (particularly if the child does not have additional health concerns).

Q. Will my baby be smart?
A. Yes! Children with Down syndrome possess so many unique gifts and while no parent is ever sure what the future may hold for their child, you can be sure that there are many things that you can do to help your child develop their full potential.

Q. What is early intervention?
A. Early intervention services are part of a national program that was first created by IDEA (Individuals with Disabilities Education Act). To be eligible for services in Florida, children must be under 3 years of age and have a confirmed disability (like Down syndrome) or an established developmental delay. These services are provided by the State and may include speech/oral motor therapy, occupational therapy and physical therapy. The Down Syndrome Association of Central Florida can help connect you to your local office to get started with these services.

Q. Does my child need early intervention? When do I begin?
A. Every baby has different needs, but we recommend that you contact the Early Steps program in order to receive an evaluation shortly after your child’s birth. Services vary based on each child’s unique needs.

Q. Will my child be able to go to a regular school?
A. Children with Down syndrome are usually included in regular academic classrooms. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The degree of mainstreaming is based on the abilities and needs of the individual; but the trend is for full inclusion in the social and educational aspects of the community.

Q. Is it possible for a person with Down syndrome to live an independent life?
A. Yes! With access to informed and effective health care, individuals with Down syndrome can now expect to live 60 years and beyond. With appropriate education, therapy and social support, the majority of people with Down syndrome can live independent and fulfilling lives.
Q. Is there local support for my child and my family?
A. Absolutely! The DSACF is here for you and your family. We have a variety of programs available including informative monthly meetings and free webinars, workshops, playgroups and support for families. We hope to meet you and your baby soon.

Q. How likely is a person to have a child with Down syndrome if he/she has a sibling with DS?
A. For the vast majority of people, having a sibling with DS does not increase one’s risk of a child with DS. That’s because 95% of all cases of DS are not inherited. The chromosomal test on the person with DS will show how likely it is to be an inherited, translocation case.

Q. How will having a child with Down syndrome impact my marriage and family?
A. Although there are certainly challenges associated with raising a child with Down syndrome, studies indicate that stress involved with raising a child with DS is lower than expected. In fact, studies reveal that parents of children with DS actually have lower divorce rates than couples who do not have a child with Down syndrome. Also according to studies, siblings of children with Down syndrome tend to be more compassionate and well-adjusted than their peers, with many developing careers in healthcare, support services and education.

Q. Where can I find more information pertaining to Down syndrome?
A. The following sites contain more information about Down syndrome:

- www.dsacf.org  Down Syndrome Association of Central Florida
- www.ndss.org  National Down Syndrome Society
- www.downsyndrempregnancy.org  Down Syndrome Pregnancy
- www.downsyn.com  Down Syndrome for New Parents
- www.ds-health.com  Down Syndrome: Health Issues
- www.globaldownsyndrome.org  Global Down Syndrome Foundation
- www.ndscenter.org  National Down Syndrome Congress

Breastfeeding FAQs

Q. Does breastfeeding hurt?
A. No! If it does, there’s something wrong with the way the baby is latched on. Take him off and begin again.

Q. Is it possible to breastfeed my baby with Down syndrome?
A. How wonderful that you want to give your baby the precious gift of your milk! Babies with Down syndrome experience special benefits from breastfeeding beyond the many advantages to typical newborns. Breast milk provides extra protection against infections and bowel problems, which are more common in babies with Down syndrome. Breastfeeding improves mouth and tongue coordination, giving a child with Down syndrome a real developmental advantage. The act of breastfeeding provides additional stimulation for your baby. Extra patience and reasonable expectations are critical when breastfeeding a baby with Down syndrome. Low muscle tone and a weak suck can impede the baby’s ability to breastfeed.

Q. How do I know that my baby is getting enough milk?
A. Once the milk comes in, the theory of “what does in one end comes out the other” works: 4-6 wet disposable diapers and 3-4 bowel movements in 24 hours usually indicates the baby is getting an adequate volume of milk.
Q. Can I breastfeed without exposing myself?
A. Absolutely! Besides special clothing that is available expressly for discreet nursing, wearing a two-piece outfit and pulling the shirt up from the waist works well. Drape a burp cloth or receiving blanket over the shoulder for coverage. Practice nursing in front of a mirror until you are comfortable.

Q. What are the benefits of breastfeeding?
A. A smarter, healthier baby who is less likely to have allergies. Less chance of breast, ovarian and cervical cancers. Getting in shape faster. A wonderful, enduring bond with your baby. So easy – nothing to fix, buy or clean.

Q. Can I breastfeed if I’m not large breasted?
A. Yes! Size has nothing to do with the milk production. Changes in the breast during early pregnancy make it possible for the breasts to make milk.

Q. Won’t I have to give up the foods I enjoy?
A. Not at all. Just a well-balanced diet, and you may wish to continue taking your prenatal vitamins while breastfeeding. Only if the baby’s father has a severe allergy to certain food(s) should you eliminate these from you – and your baby’s – diet.

Q. Doesn’t breastfeeding tie you down?
A. Not really. During the first few months, a breastfed baby is very portable! Just pack a few diapers and maybe a change of clothes for the baby and you’re ready to leave. Later, you may want to express or pump some of your special milk to leave for your baby while you’re away.

Q. How long does it take to breastfeed?
A. Soon after the baby is born, feeding usually takes 15-20 minutes per side and most mothers offer both sides at each feeding. If the baby falls asleep, start the next feeding with the breast that didn’t get nursed at the last feeding. Later, as the baby becomes more efficient, an entire feeding may only take 15-20 minutes.

Q. What’s so special about human milk?
A. Your body makes it especially for your baby. Cow’s milk was designed for baby calves. Every time your baby nurses, he gets protection from exactly what you and he have come in contact with. Plus exactly what he needs for brain development and perfect growth.

Q. Why do people say breastfeeding is important?
A. At birth, a baby is immune to everything his mother is but has no functional immune system of his own. At six weeks, the faint stirrings of immunity begin. By the time the baby is six months old, he will have a functional, but still immature system to help him keep healthy and allergy free. Breast milk gives the baby all the immunities he needs until he can make his own.
Q. Why bother breastfeeding when I know I’ll be returning to work (or school)?

A. Once you return to school or work, you could either pump your milk for your baby to use the next day or choose to give him bottles while you’re away. Although you might need to pump for a few days until your breasts don’t feel so full anymore, your body adjusts as it will when the baby sleeps through the night.

Q. Will I be able to satisfy my baby?

A. The human breast is designed to refill the milk that is used: the policy of supply and demand. Before bottles were prevalent, we all assumed that every mother would feed her own baby and there were no worries about this. Allowing the baby to nurse until he stops every 2-3 hours will ensure that you will make enough milk.

Q. What about the baby’s father? Won’t he feel left out?

A. There are lots of things dads can do with a baby besides feeding him. Bathing provides lots of skin-to-skin contact and fun. Sitting by you while you nurse the baby and rubbing between your shoulder blades usually gives the baby a milk mustache! Listen for the rapid swallowing. Rocking, holding, cuddling and playing with the baby will make Dad feel a part of the action.

Q. What if I have questions or need help?

A. Contact the local LaLeche League or the lactation specialist at your hospital or pediatrician’s office.

Q. Won’t the baby bite me?

A. When a baby is properly nursed, he will first bite his own tongue! Teeth usually do not appear until the baby is 5-6 months old. By then, you will be alert to his cues.

Q. Will I spoil my baby holding/nursing him so often?

A. Mothers throughout history have always known, and research now shows, that babies are happiest, healthiest and smartest, if they are kept in close contact with their mother or another family member most of the time. Asleep or awake, happy or sad, babies like to feel and smell your warm embrace. Research shows babies grow faster and learn about their world more readily when up on mother’s level. There’s more for the baby to see when he is with you while you go about your daily business than when lying flat in a crib or carriage. Babies cry much less and expend less energy that way. Many newborns sleep more deeply when held against your body. This type of approach is very respectful of your baby’s feeling and is sometimes called “attachment parenting”.

Nursing a baby on demand or by request assures you a bountiful milk supply (the more a baby sucks the more milk you make) and also makes you available to comfort your child, soothe a pain or simply provide the human contact your baby needs. His mouth is the most sensitive area of his body and sucking feels good to him. Unlike a pacifier, which can fall on the floor and get dirty, your nipples are always safe. No need to watch the clock; watch what your baby is telling you. He may be thirsty, want a snack or a full course meal.

Q. How can I care for my other child(ren) while breastfeeding my infant?

A. When the new baby arrives, sometimes an older child will feel left out. Make sure to assure the older child that he is still loved – with plenty of hugs and kisses. Remind him or her that they were tiny once and needed to be breastfed a lot. Show them photos of when they were small(er). Arrange a place on the sofa where you can comfortably feed your infant and where the toddler can snuggle close too. Or put a small chair and table near your rocking chair where the toddler can play while you are breastfeeding the little one. See The Womanly Art of Breastfeeding for ideas on toys and games to keep your older child occupied while you are feeding the baby. Use a baby sling to nurse and still be up and around. When the baby is asleep, give your undivided attention to the other child(ren). Fill up their “love wells” when you have time and they’re less likely to have an urgent need or get into squabbles together when it is time to meet the new baby’s needs.

This information is courtesy of La Leche League International. For more information please visit the website www.llli.org