

Congratulations!

The birth of your new baby is a time for celebration and the feeling of joy! Your baby may not be as you have imagined, but rest assured that your baby is more like other babies than different. You may be feeling afraid and uncertain, which is perfectly normal. Most parents experience this when they hear their child has Down syndrome. Take a deep breath and relax. Now is the time for you to get to know your baby and love each other.

Down syndrome is the most common chromosomal anomaly. Your child has had Down syndrome since conception, *nothing you did or didn't do, before or during your pregnancy*, caused this. To help you to make informed decisions regarding your child, we offer an abundance of relevant information about Down syndrome to help you to make informed decisions regarding your child. Please take your time in searching through our website, getting acquainted with our families and becoming more familiar with the links on Down syndrome. It is important to caution our new parents to be sure that the information you access is up to date and relevant to individuals needs today. We are here to answer any questions you may have. If during your research you find any questionable information or are uncertain or unclear about any topic, we will be delighted to help find the answers to your questions.

Accept no limitations! The future is bright. The first generation of children with Down syndrome who have benefited from early intervention and inclusive environments are opening new doors. People with Down syndrome are leading meaningful and productive lives. They are now graduating from school, attending college, and having fulfilling careers and relationships.

The Down Syndrome Guild of Dallas has trained parent-to-parent counselors, each of whom has a child with Down syndrome. We would love to talk with you and let you know how we can help. If you are interested in talking to another parent, please call the Down Syndrome Guild of Dallas at 214-267-1374 or click dsged@sbcglobal.net.

The best thing you can do right now is love, nurture and bond with your baby like you would any other baby. Congratulations, you are about to embark on amazing journey!

Warmest Regards,

Down Syndrome Guild of Dallas New Parent Support Group



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congratulations



Congratulations on the birth, or expected birth, of your baby! We understand that your baby may have Down syndrome. You probably have a million questions, concerns, and fears right now. That's okay. The most important thing to keep in mind is that this diagnosis is not as "life changing" as the fact that you have a new baby. And in most ways, your baby will be just like other infants. Every baby needs to be fed, held, and most of all, loved.

There will be challenges in raising your child, but there will also be many, many joys. It's normal to be nervous about what lies ahead, but remember that Down syndrome is a condition your baby has, it is not who your baby is. Now is the time to begin learning all you can about Down syndrome and the local services available to you. This New Parent Guide is a great place to start.

creed of babies with down syndrome

My face may be different
But my feelings the same.
I laugh and I cry
And take pride in my gains.

I was sent here among you
To teach you to love
As God in the heavens
Looks down from above.



To Him, I'm no different
His love knows no bounds;
It's those here among you
In cities and towns

That judge me by standards
That man has imparted,
But this family I've chosen
Will help me get started.

For I'm one of the children
So special and few
That came here to learn
The same lessons as you.

That love is acceptance,
It must come from the heart;
We all have the same purpose,
Though not the same start.

The Lord gave me life
To live and embrace,
And I'll do it as you do...
But at my own pace.

the special mother

by Erma Bombeck

Most women become mothers by accident, some by choice, a few by social pressures and a couple by habit. This year nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen? Somehow I visualize God hovering over earth selecting his instruments for propagation with great care and deliberation. As He observes, He instructs His angels to make notes in a giant ledger.

“Armstrong, Beth; son. Patron saint...give her Gerard. He’s used to profanity.”

“Forrest, Marjorie; daughter. Patron saint, Cecelia.”

“Rutledge, Carrie; twins. Patron saint, Matthew.”

Finally He passes a name to an angel and smiles, “Give her a handicapped child.”

The angel is curious. “Why this one God? She’s so happy.”

“Exactly,” smiles God, “Could I give a handicapped child to a mother who does not know laughter? That would be cruel.”

“But has she patience?” asks the angel.

“I don’t want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock and resentment wears off, she’ll handle it.”

“I watched her today. She has that feeling of self and independence that is so rare and so necessary in a mother. You see, the child I’m going to give her has her own world. She has to make her live in her world and that’s not going to be easy.”

“But, Lord, I don’t think she even believes in you.” God smiles, “No matter, I can fix that. This one is perfect - she has just enough selfishness.” The angel gasps - “Selfishness? Is that a virtue?”

God nods. “If she can’t separate herself from the child occasionally, she’ll never survive. Yes, here is a woman whom I will bless with a child less than perfect. She doesn’t realize it yet, but she is to be envied. She will never take for granted a ‘spoken word’.” She will never consider

the special mother

a “step” ordinary. When her child says ‘Momma’ for the first time, she will be present at a miracle, and will know it!”

“I will permit her to see clearly the things I see...ignorance, cruelty, prejudice....and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life, because she is doing My work as surely as if she is here by My side.”

“And what about her Patron saint?” asks the angel, his pen poised in mid-air.

God smiles, “A mirror will suffice.”

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jon will's aptitudes

by George Will
Columnist for Washington Post, TV Personality and Author

Jon Will, the eldest of my four children, turns 21 this week and on this birthday, as on every other workday, he will commute by subway to his job delivering mail and being useful in other ways at the National Institutes of Health. Jon is a taxpayer, which serves him right: He voted for Bill Clinton (although he was partial to Pat Buchanan in the primaries).

The fact that Jon is striding into a productive adulthood with a spring in his step and Baltimore's Orioles on his mind is a consummation that could not have been confidently predicted when he was born. Then a doctor told his parents that their first decision must be whether or not to take Jon home. Surely 21 years later fewer doctors suggest to parents of handicapped newborns that the parental instinct of instant love should be tentative or attenuated, or that their commitment to nurturing is merely a matter of choice, even a question of convenience.

Jon has Down syndrome, a chromosomal defect involving varying degrees of mental retardation and physical abnormalities. Jon lost, at the instant he was conceived, one of life's lotteries, but he also was lucky: His physical abnormalities do not impede his vitality and his retardation is not so severe that it interferes with life's essential joys--receiving love, returning it, and reading baseball box scores.

One must mind one's language when speaking of people like Jon. He does not "suffer from" Down syndrome. It is an affliction, but he is happy--as happy as the Orioles' stumbling start this season will permit. You may well say that being happy is easy now that ESPN exists. Jon would agree. But happiness is a species of talent, for which some people have superior aptitudes.

Jon's many aptitudes far exceed those few that were dogmatically ascribed to people like him not long ago. He was born when scientific and social understanding relevant to him was expanding dramatically. We know much more about genetically based problems than we did when, in the early 1950s, James Watson and Francis Crick published their discoveries concerning the structure of DNA, the hereditary molecule, thereby beginning the cracking of the genetic code. Jon was born the year before *Roe v. Wade* and just as prenatal genetic tests were becoming routine. Because of advancing science and declining morals, there are fewer people like Jon than there should be. And just in Jon's generation much has been learned about unlocking the hitherto unimagined potential of the retarded. This begins with early intervention in the form of infant stimulation. Jon began going off to school when he was three months old.

Because Down syndrome is determined at conception and leaves its imprint in every cell of the person's body, it raises what philosophers call ontological questions. It seems mistaken to say that Jon is less than he would be without Down syndrome. When a child suffers a mentally limiting injury after birth we wonder sadly about what might have been. But a Down person's life never had any other trajectory. Jon was Jon from conception on. He has seen a brother two years younger surpass him in size, get a driver's license and leave for college, and although Jon would be forgiven for shaking his fist at the universe, he has been equable. I believe his serenity is grounded in his sense that he is a complete Jon and that is that.

Some of life's pleasures, such as the delights of literature, are not accessible to Jon, but his most poignant problem is that he is just like everyone else, only a bit more so. A shadow of loneliness, an irreducible apartness from others, is inseparable from the fact of individual existence. This entails a sense of incompleteness--we **are** social creatures--that can be assuaged by marriage and other friendships, in the intimacy of which people speak their hearts and minds. Listen to the wisdom whispered by common locutions: We speak of "unburdening ourselves" when we talk with those to whom we talk most freely.

Now, try to imagine being prevented, by mental retardation and by physical impediments to clear articulation, from putting down, through conversations, many burdens attendant on personhood. The shadow of loneliness must often be somewhat darker, the sense of apartness more acute, the sense of incompleteness more aching for people like Jon. Their ability to articulate is, even more than for everyone else, often not commensurate with their abilities to think and feel, to be curious and amused, to yearn.

Because of Jon's problems of articulation, I marvel at his casual everyday courage in coping with a world that often is uncomprehending. He is intensely interested in major league baseball umpires, and is a friend of a few of them. I think he is fascinated by their ability to make themselves understood, by vigorous gestures, all the way to the back row of the bleachers. From his season-ticket seat behind the Orioles dugout, Jon relishes rhubarbs, but I have never seen him really angry. The closest he comes is exasperation leavened by resignation. It is an interesting commentary on the human condition that one aspect of Jon's abnormality--a facet of his disability--is the fact that he is gentleness straight through. But must we ascribe a sweet soul to a defective chromosome? Let us just say that Jon is an adornment to a world increasingly stained by anger acted out.

Like many handicapped people, Jon frequently depends on the kindness of strangers. He almost invariably receives it, partly because Americans are, by and large, nice, and because Jon is, too. He was born on his father's birthday, a gift that keeps on giving.

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"WE CANNOT FASHION OUR CHILDREN AFTER OUR DESIRES,
WE MUST HAVE THEM AND LOVE THEM
AS GOD HAS GIVEN THEM TO US."
- JOHANN WOLFGANG VON GOETHE



Getting Started: Important Things to Know

Women, Infants & Children's Nutrition Program (WIC)

Your child may automatically qualify for WIC if he/she receives Medicaid, Temporary Assistance to Needy Families or Food Stamps. WIC provides free formula and nutritious foods for pregnant women and children from birth to age 5. Gross income must fall at or below 185% of federal poverty income levels to qualify. See contact information under the Resources tab.

Early Childhood Intervention Services (ECI)

ECI is a statewide program for families with children, birth to three, with disabilities and developmental delays. ECI supports families to help their children reach their potential through developmental services. Services are provided by a variety of local agencies and organizations across Texas.

ECI provides evaluations and assessments, at no cost to families, to determine eligibility and need for services. Families and professionals work as a team to plan appropriate services based on the unique needs of the child and family. ECI asks families who can afford to do so, to share in the cost of services. The amount a family pays for ECI services is determined using a sliding fee scale and is based on family size and income after allowable deductions. No child and family will be turned away because of an inability to pay.

ECI goes to families and focuses on working with the child and family in their natural environment, such as at home, grandma's, or a child care center. Essentially, it's where children live, learn and play.

ECI is here to help and can become an important resource for all families. For more information about ECI or to refer a child, call the Department of Assistive and Rehabilitative Service (DARS) Inquiries Line at **1-800-628-5115**. Contact numbers and providers can be found behind our Resource tab.

Medicaid Home and Community-Based Waiver Programs

Texas currently has seven different Medicaid waiver programs designed to allow Medicaid funds to be available to provide individuals with disabilities the opportunity to receive supports and services in their community as an alternative to institutional care. These waivers are administered through the Texas Department of Aging and Disability Services (DADS). Medicaid waiver services can be especially helpful to families caring for children with disabilities. Contact numbers for these Waivers are behind the Resource tab.

getting started

Oral Motor Skills

Almost all children with Down syndrome will have oral motor issues ranging from very mild to severe. It is recommended by experts that you try to get your baby to suck a pacifier. This may take some trial-and-error to determine the pacifier that works for them, and some babies just won't take a pacifier. Sucking a pacifier will build oral motor control, and helps develop the muscles needed for sucking, drinking, eating, and speech.

Muscle Tone

Children with Down syndrome have low muscle tone and extremely limber joints. This combination delays development in crawling and walking. When your child is lying on his/her back they will probably lie with legs and arms splayed open to each side. It will be more beneficial for them to lie on their side with a wedge to keep them from turning to their back. This will keep legs together and arms at mid-line. When holding your baby, try to keep both arms in front of their body, not falling out beside them.



questions and answers

Questions & Answers about DOWN SYNDROME

What is Down syndrome?

Down syndrome is a chromosomal disorder characterized by the presence of an extra #21 chromosome. Instead of having 46 chromosomes in each of his/her cells, a person with Down syndrome has 47. The extra chromosome may be derived from either the egg or the sperm. It is believed that during cell division of a sperm or egg, the two #21 chromosomes do not separate properly (nondisjunction). Thus, one cell will have an extra #21 chromosome which later, if united with a normal germ cell which has among others one #21 chromosome, may lead to trisomy 21. The first cell at conception then has 47 chromosomes instead of a "normal set" of 46 chromosomes. When this cell with three #21 chromosomes continues to multiply, and the pregnancy is carried to term, a baby with Down syndrome will be born. This form of chromosome error, trisomy 21, is found in about 95% of persons with Down syndrome.

The five percent of babies with Down syndrome who do not have trisomy 21 may have translocation, mosaicism, or partial trisomy. In translocation Down syndrome, there are also three copies of the #21 chromosome. However, one of the #21 chromosomes is attached or translocated on another chromosome, usually a #14, #21, or #22 chromosome. Three to four percent of children with Down syndrome have translocation. About one third to one half of translocations are inherited from one of the parents. When this happens, the carrier parent has the normal amount of genetic material, however one of the #21 chromosomes is attached to another chromosome. As a result, this individual's total chromosome count is 45 instead of 46. The carrier parent is clinically unaffected because there is no loss or excess of genetic material. Doctors refer to a parent like this as a balanced carrier.

Another form of Down syndrome is known as mosaicism, which affects about one percent of all people with Down syndrome. In mosaicism, a faulty cell division most often occurs in one of the earliest cell divisions after conception. This is in contrast to other types of Down syndrome when the error in cell division occurs before fertilization. As in trisomy 21, something causes one of the cells to divide incorrectly. But when this occurs in one of the early cell divisions, only some of the cells of the growing embryo have the extra #21 chromosome and the other cells have the normal number of chromosomes. Depending on the ratio of normal cells to trisomic cells, the child may have fewer Down syndrome features as well as higher cognitive abilities.

Although details of the mechanism of nondisjunction are for the most part unknown, the presence of three copies of the #21 chromosome causes a genetic imbalance that alters the typical course of growth and development of the fetus and child with Down syndrome.

questions and answers

What causes Down syndrome?

Down syndrome occurs in approximately one out of every 800 to 1,000 live births; it is one of the most often observed chromosome anomalies. Scientists have investigated the causes of Down syndrome for the past century. So far, its exact cause has eluded discovery. Although many factors have been considered to be possible causes, the age of the mother is the most often discussed factor related to the likelihood of having a baby with Down syndrome. It has been known for some time that the risk of having a child with Down syndrome increases with the advancing age of the mother, i.e., the older the mother, the greater chance that she may give birth to a child with Down syndrome. The risk at age 20 for instance is about 1 in 1,600, the risk at age 35 is 1 in 365 and the risk at 40 is 1 in 100. However, because there are more younger women having babies, 75-80% of all children with Down syndrome are born to women under 35 years of age.

If I already have a child with Down syndrome, is the risk higher that I will have another child with Down syndrome?

If your baby has trisomy 21, the risk for having another child with Down syndrome is approximately 1 in 100 or 1% in addition to the mother's age related risk. For families who have a baby with translocation Down syndrome, the risk of recurrence is also about 1 in 100 unless the condition is inherited from one of the parents. The risk of recurrence depends on the type of translocation and the sex of the carrier parent.

Are any prenatal tests available to detect Down syndrome?

Yes. There are several types of testing available.

Screening Tests: Screening tests are used to look for potential problems and to identify those who are at high risk of having a baby with a genetic disorder.

The triple screen and the alpha-fetoprotein plus, and more recently, the quad test measure the amounts of certain hormones and proteins in the blood including alpha-fetoprotein, human chorionic gonadotropin, unconjugated estriol and inhibin. The results of these tests together with the woman's age, will provide an estimate of her risk of having a child with Down syndrome. These tests are usually performed between the 14th and 16th week of gestation. Approximately 60-80% of fetuses with Down syndrome can be identified prenatally by considering the mother's age and employing these screening tests.

In addition, ultrasound examinations are almost always performed. During an ultrasound examination the physician looks for "markers," such as a thickening of the skin at the back of the neck (nuchal fold), bright spots on the kidneys or heart, short arms or legs, reduced head size, congenital heart disease, and gastrointestinal problems. If any of these "markers" are observed, diagnostic testing is generally recommended.

Diagnostic Testing: Diagnostic testing tells whether or not the baby has the condition. However, there is no diagnostic test that is 100% reliable. Amniocentesis and chorionic villus sampling are the two diagnostic tests most often used to determine whether the fetus has Down syndrome.

questions and answers

Amniocentesis is typically performed around the 16th week of pregnancy. Before the procedure, an ultrasound examination is done which shows the location of the placenta, the amniotic cavity, and the fetus. During the procedure, a needle is inserted into the amniotic cavity through the mother's abdomen. A small amount of amniotic fluid is obtained and analyzed. The amniotic fluid contains cells from the fetus, which are cultured and then examined to determine whether or not the fetus has Down syndrome. It generally takes 12 to 20 days to obtain results. Amniocentesis has about a two percent rate of miscarriage as well as other side effects, such as infection, bleeding, cramping, and needle puncture of the fetus.

Chorionic villus sampling (CVS) is done in early pregnancy, usually between nine and twelve weeks of gestation. Following an ultrasound examination, a thin tube is inserted through the vagina and a small piece of placental tissue is obtained. Because the cells from the chorionic villi are fetal tissue, they can be cultured and then examined for chromosome abnormalities in one week to ten days. In terms of side effects, CVS is slightly more likely than amniocentesis to be followed by miscarriage or other complications such as infections, bleeding, and leaking of amniotic fluid.

What are the physical characteristics of Down syndrome?

The following characteristics are most commonly associated with Down syndrome, but can also be found in the general population. There is some variety of physical features among babies with Down syndrome; not every baby possesses all of the characteristics. Moreover, there is no correlation between the number of characteristic features a baby has and the child's cognitive ability.

Babies with Down syndrome usually have low muscle tone called hypotonia. This means that their muscles appear relaxed and feel "floppy." The baby's face may be broader and his/her nasal bridge may be flatter than usual. Often children with Down syndrome have a small nose. The child's eyelids may appear to slant upward and may also have small folds at the inner corners (epicanthal folds). The baby's mouth may be small and the roof of the mouth may be narrow. The baby's ears are often small and the upper part of the ear may fold over. Babies with Down syndrome usually have small heads. The difference in size, however, is not usually noticeable. The back of the head may be flatter and the neck may appear shorter. In newborns, there may be loose folds of skin on the back of the neck, but these tend to disappear later with advancing age.

The child's hands may be smaller, and his/her fingers may be shorter than other children's. In about 50% of children with Down syndrome only one palmar crease is observed, and the fifth finger may be curved slightly inward. Usually the feet of babies with Down syndrome appear fairly normal, but there may be a wide gap between the first and second toe.

questions and answers

Because children with Down syndrome have an extra #21 chromosome, they may have features that resemble other babies with Down syndrome in some way. However, they will also resemble their parents, brothers, and sisters.

What are the developmental aspects?

The baby with Down syndrome will grow and develop like other babies. He/she will do all the things a typical child does, only somewhat later. Compared with typical children, individuals with Down syndrome are usually smaller and their development is somewhat slower. For example, instead of walking at 12 to 14 months, a child with Down syndrome may learn to walk between 18 and 36 months. Most children with Down syndrome will display a delay in their speech and language development. It should be noted that there is a wide variation in the mental, behavioral, and developmental progress in children with Down syndrome. A caring and enriching home environment, early intervention, and improved special education services have a positive influence on the child's development.

Do all children with Down syndrome have mental retardation?

No. A few children with Down syndrome are not mentally retarded, they may function in the borderline or low average range. The vast majority of children with Down syndrome function in the mild to moderate range of mental retardation. Children with Down syndrome often attend regular schools in regular education classes with differing levels of support. Most graduate from high school and some are enrolled in post secondary educational programs including colleges and vocational programs.

What about adults with Down syndrome? Where do they live?

Today, adults with Down syndrome have choices about where they live and with whom they live. Some live in apartments, condominiums, or houses with roommates and/or with support services, and some adults choose to remain in homes with their parents or siblings.

Do adults with Down syndrome work?

Adults with Down syndrome are working at a variety of jobs ranging from regular competitive jobs in the community to supported employment or sheltered employment. People with Down syndrome are clerical workers, computer operators, assistant coaches, photographers, teacher assistants, etc. People with Down syndrome are becoming more and more contributing and tax-paying members of their communities.

What is the life expectancy of people with Down syndrome?

Improved medical care has primarily prolonged the life span of people with Down syndrome. It is not unusual for people with Down syndrome to live into their 50's, 60's, and even 70's.

you are not alone

You Are Not Alone: For Parents When They Learn That Their Child Has a Disability

by Patricia McGill Smith

If you have recently learned that your child is developmentally delayed or has a disability (which may or may not be completely defined), this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a “black sack” being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as “having a knife stuck” in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help yourself through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and this enormous challenge. One of the first reactions is *denial*—“This cannot be happening to me, to my child, to our family.” Denial rapidly merges with *anger*, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of *grief* and inexplicable *loss* that one does not know how to explain or deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and some knowledge of the child's future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: “What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?” Then other questions arise: “Will he ever learn? Will he ever go to college? Will

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he or she have the capability of loving and living and laughing and doing all the things that we had planned?”

Other unknowns also inspire fear. Parents fear that the child’s condition will be the very worst it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of persons with disabilities one has known. Sometimes there is guilt over some slight committed years before toward a person with a disability. There is also fear of society’s rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers or sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is *guilt*—guilt and concern about whether the parents themselves have caused the problem: “Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?” For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn’t tell me. Much self-reproach and remorse can stem from questioning the causes of the disability.



Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, “Why me?” or “Why my child?”, many parents are also saying, “Why has God done this to me?” How often have we raised our eyes to heaven and asked: “What did I ever do to deserve this?” One young mother said, “I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship.”

what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and

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are just not on the same wavelength as the person who is trying to communicate with them about their child's disability.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they will know that *they are not alone*. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a disability is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a boy with mental retardation.

My first recommendation is to try to find another parent of a child with a disability, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent to Parent Programs. The National Information Center for Children and Youth with Disabilities (NICHCY) has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to NICHCY to get that local information.

you are not alone

Talk with Your Mate, Family, and Significant Others

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength. Understand that you each approach your roles as parents differently. How you will feel and respond to this new challenge may not be the same. Try to explain to each other how you feel; try to understand when you don't see things the same way.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another may be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Even though it may not seem possible, good things will continue to happen each day. Worrying about the future will only deplete your limited resources. You have enough to focus on; get through each day, one step at a time.

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Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the word.

Seek Information

Some parents seek virtually “tons” of information; others are not so persistent. The important thing is that you request accurate information. Don't be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child.

Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports. If you are not a naturally organized person, just get a box and throw all the paperwork in it. Then when you really need it, it will be there.



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Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials and, sometimes, because of their professional manner. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how they are feeling. The strongest fathers of children with disabilities whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Natural Feelings of Bitterness and Anger

Feelings of bitterness and anger are inevitable when you realize that you must revise the hopes and dreams you originally had for your child. It is very valuable to recognize your anger and to learn to let go of it. You may need outside help to do this. It may not feel like it, but life will get better and the day will come when you will feel positive again. By acknowledging and working through your negative feelings, you will be better equipped to meet new challenges, and bitterness and anger will no longer drain your energies and initiative.



Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is, truly, always a positive side to whatever is occurring. For example, when my child was found to have a disability, one of the other things pointed out to me was that she was a very healthy child. She still is. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have ever raised. Focusing on the positives diminishes the negatives and makes life easier to deal with.

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Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of the country, assistance is available to help you with whatever problems you are having. NICHCY's [*State Resource Sheets*](#) list contact persons who can help you get started in gaining the information and assistance you need. While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: Get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child is actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

Decide How to Deal With Others

During this period, you may feel saddened by or angry about the way people are reacting to you or your child. Many people's reactions to serious problems are caused by a lack of understanding, simply not knowing what to say, or fear of the unknown. Understand that many people don't know how to behave when they see a child with differences, and



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they may react inappropriately. Think about and decide how you want to deal with stares or questions. Try not to use too much energy being concerned about people who are not able to respond in ways you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, “When a problem arises and you don’t know what to do, then you do whatever it was that you were going to do anyway.” Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This is Your Child

This person is your child, first and foremost. Granted, your child’s development may be different from that of other children, but this does not make your child less valuable, less human, less important, or in less need of your love and parenting. Love and enjoy your child. The child comes first; the disability comes second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost universal among parents. In this article, there are many recommendations to help you handle feelings of separateness and isolation. It helps to know that these feelings have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

Article courtesy of National Dissemination Center for Children with Disabilities (NICHCY).

About the Author

Patricia Smith brings much personal and professional experience to the national parent and disability movement. She is currently the Executive Director of the National Parent Network on Disabilities. She has served as the Acting Assistant and Deputy Assistant Secretary in the Office of Special Education and Rehabilitative Services, in the U.S. Department of Education. She has also served as the Deputy Director of NICHCY, where she wrote and first published You Are Not Alone. She has traveled to almost every corner of the United States, as well as internationally, to share her hope and experience with families who have a member with a disability.

Ms. Smith has seven adult children, the youngest of whom has multiple disabilities. She also has a seven year old adopted grandson who has Down syndrome.