

www.FamilyConnect.org

Learning that Your Child Is Visually Impaired

There is no right or wrong way to cope with the news that your child is blind or visually impaired. Whatever you're feeling—anger, sorrow, guilt, confusion, anxiety, or fear—you need to know that your emotions are natural and shared by virtually all parents faced with problems that affect their child's health and well-being.

There are a number of strategies that can help you balance your life and your concern for your visually impaired child.

Acknowledge Your Feelings

Recognize that each parent responds differently to having a child with a visual impairment. Try not to compare yourself or your spouse to other parents or criticize yourself because at times you may feel depressed, angry, or have other distressing emotions.

Take Good Care of Yourself

You're entitled to take care of your own life without feeling guilty. In fact, you need to. Eating what's good for you, getting enough sleep, relaxing as much as possible, and continuing activities that are rewarding to you are all important aspects of maintaining an effective day-to-day life. Good health is essential to keeping up your spirits as well as your physical strength and, in that way, helping your family and your child.

Stay Connected

Getting emotional support from people who care about you is crucial. When you feel less than perfect, you may have a tendency to withdraw from friends and sometimes from family, too. Although you may feel shaken and exhausted at times, try to stay in touch with your friends, family, and others who can boost your spirits and help you cope.

Find a Good Listener

Many people find that simply talking about what's bothering them is a great relief. Choose someone you're comfortable with, who won't judge you, and who will just listen to how you feel. An empathetic ear is invaluable for most of us as we try to sort out what we feel and what to do.

Give Yourself Time to Adjust

Adjusting to the news of your child's visual impairment is part of a continuing process. In many ways, every family is in constant transition, and it may be helpful to keep that in mind. Give yourself and your family time to absorb this situation, and begin to see your circumstances in terms of what steps you can take to ensure your child's successful future.

Connect with Other Families

Get in touch with other families who have had similar experiences. Many parents who've raised a visually impaired child have a lot of expertise to share with you. They can help you find contacts, current medical and educational information, and useful resources. They can also offer you tremendous emotional support along with suggestions and tips from their own experiences raising a child who is visually impaired. You can begin making connections by going to the [message boards](#) on FamilyConnect. Another way to meet parents is by joining [The National Association for Parents of Children with Visual Impairments \(NAPVI\)](#). You can get a list of other national and local parent support groups under [Find Services](#) on FamilyConnect.

Work with Knowledgeable Professionals

Consult with professionals who are specialists in blindness or low vision about your child's eye condition. University-affiliated hospitals, professional organizations, and national organizations in the field of visual impairment are good sources of referrals and other information. This site is also a good source of information about finding [specialized professionals and helpful organizations](#).

Become Informed About Your Child's Eye Condition

Learn as much as you can about your child's eye condition. Some excellent sources of information include: early intervention teachers and therapists, medical doctors, eye care and low vision specialists, libraries, the Internet, national organizations serving people with visual impairments, and other families with a child that is visually impaired. When talking with your child's doctor, be sure to ask any and all questions you have and request explanations of any answer that isn't clear to you.

Establish Long-term Relationships with Key Medical and Other Service Providers

Every family needs a trusted group of experts who can offer sound advice and ongoing help. You may find it helpful if your own group includes the following professionals:

- A pediatrician
- A pediatric ophthalmologist or optometrist
- Various other specialists, such as an early interventionist, a teacher of students with visual impairments, an orientation and mobility specialist, a physical therapist, a speech and language therapist, or a psychologist, depending on your child's specific needs

Seek Out Intervention Services

If your child is under age 3, work with an early childhood interventionist. Babies who are visually impaired are eligible for early intervention services. The professionals you'll meet through early intervention have skills and experience that can help your family through the first few years of your baby's life. For information and referral to services near you consult the lead agencies for early intervention in your state.

If your child is over age 3, work with a teacher of students with visual impairments. Children who have a visual impairment that impacts their education typically qualify for services from a teacher of students with visual impairments and an orientation and mobility specialist. These professionals work with children to help maximize their educational

potential. Contacting your school district's special education office is the first step to locating services for your child.

Keep Good Records

Set aside a place in your home for maintaining files on your child's medical condition and school status. It's a good idea to separate medical from school files, but any system that helps you keep important information organized and easy to locate is invaluable. Save copies of:

- Doctor's reports
- Reports from other consultants or specialists
- Correspondence between you and any educational and medical program or agency with which you've had contact
- Copies of your child's Individualized Family Service Plan (IFSP); Individualized Education Program (IEP) once your child begins school; and copies of other official reports
- Results of any assessments of your child

Know the Law

Knowing what your child is entitled to is invaluable information. It's your guide to knowing what to ask for and how to ensure that your child gets the services she needs. Important laws include the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA).

Find out the names of your local and state legislators and how to reach their neighborhood offices. They can be very helpful when you need information about contacting the appropriate person to help your child or confirming what your child's rights are under the law.

Focus on the Positive

It's easy to put your own needs on the back burner when you're dealing with the news of your child's visual impairment. Don't forget about yourself or feel that you're not entitled to do the things that you enjoy. Remember that first and foremost you child is a child and not a disability. Enjoy him for who he is. Nurture, play, discipline, and give your child the love and attention he needs. This will help in his development and you'll feel better too.

Family Relationships

The arrival of a new baby is a major family event that affects everyone—you especially, but also your baby's siblings, grandparents, uncles, aunts, and cousins. They are all going to be affected, in one way or another, by your child's visual impairment.

Your Spouse or Partner

You and your spouse may have a multitude of feelings that affect you deeply. If you can be supportive of one another; focus on the love you share as a family; and recognize the strength you can gain from that, you may find it easier to cope with conflicting feelings that can interfere with your ability to think and act constructively. Try to set aside time regularly for yourselves, individually and as a couple. Keep doing the things you enjoyed doing alone and those you enjoyed doing together, even if you can't do them as often or as easily.

Give yourselves time—weeks, months, and longer, if necessary. It takes time to adjust to any new situation and to learn ways of dealing well with your circumstances and your feelings. Life is an ongoing process, a series of transitions, and you're in transition now. It may be helpful to remember just that.

But if you can't shake the feeling of being overwhelmed by immediate concerns and anxiety about the future, you may want to consider seeking counseling or other external support.

Your Other Children

If you have other children, the fact that their baby brother or sister is visually impaired may have a strong impact on them. Depending on how old they are, their reactions will vary. As they get older, they'll understand more, need more information, and may want to help their little brother or sister. At times they may also be jealous of the extra time you spend with your visually impaired child. They're going to want—and deserve—your time and attention too. Realistically, your visually impaired child is going to require more of your time, attention, and energy, but you don't want to lose sight of your other children's needs.

Grief and Other Feelings

Recognize that brothers and sisters—and everyone in the family—may grieve for the "normal" baby they anticipated. At times they may be angry, depressed, resentful, jealous, or in denial about their brother's visual impairment. Those feelings are normal. After all, you probably have them too. But if you find that your older child's behavior has changed in ways that worry you—that her school work has suffered; that he's dropped out of his weekly softball game; that she's stopped going to the mall with friends—consider seeking professional help.

Expectations

You can't expect a big sister to be "on duty" all the time to help her visually impaired brother. While it's a good idea to involve her in his care sometimes, that shouldn't interfere with her own childhood fun. You might ask her to pick one meal a day to help him with his eating skills, or ask your son to help his little sister learn to play with her toys from time to time.

Your other children need a fair share of your time. Try scheduling outings with them to do things they especially enjoy. Have a "movie date" with your son every couple of weeks—and leave the choice to him. Go to your daughter's soccer game as often as you can and have a special treat together on the way home.

Depending on their ages, keep your other children up to date on what's going on with their visually impaired sister—whether it's a new medical procedure or the decision about which preschool she'll go to when she's three. While you don't want to burden them with details, share as much information as you think is appropriate about what's happening or may happen soon so they're not taken by surprise or left to worry about the unknown.

If your baby gets early intervention services and your other children are toddlers or preschoolers, they may be jealous when people come to your house with what they think are great toys and they don't get to play with them. Talk to the professionals who visit about ways they can involve your other children during their home visits. If you take your child to a center-based program, ask the professionals there for ways to get your other children involved.

Your older child may feel that he's the only one in the world with a visually impaired sister. If you're in a parents group or an early intervention program, you'll meet people who can probably put you, and him, in touch with other kids in a similar situation so they can compare experiences and learn from one another.

Grandparents

The relationship between grandparents and grandchildren is often very special. But it may be hard for your parents to know how to behave with a visually impaired grandchild. Like brothers and sisters, grandparents will grieve for the "normal" grandchild they expected. They'll probably need your help to understand the importance of treating your little girl the same as their other grandkids—that she needs their love and support; will learn to do the things other children do, although differently; and is an important part of the family.

If you and your family usually do things together, such as fishing, having a barbeque, or sharing the cooking and celebration of Thanksgiving, don't stop because your child is visually impaired. Try to help family members learn how to include your child in activities you've all enjoyed together in the past. Your early intervention team, if you're working with one, may be able to suggest some strategies. The staff of national organizations mentioned on this site and, of course, other families may also be of help.

Talking to Family and Friends about Your Child's Visual Impairment

When Bob and Marcia learned that their infant son, Karl, was blind, they were too stunned to talk about it with family or friends. But as Thanksgiving approached, they realized that they couldn't keep the news about 3-month-old Karl's blindness to themselves any longer. They were spending the holiday, as they always did, with Bob's large family and wanted the family to know, but couldn't imagine how to tell them.

On Thanksgiving Day, when dinner was over, Bob decided that this was the time to finally do it. Holding his son, he told everyone about learning that Karl was blind. There was silence in the room, and then his 7-year-old nephew spoke up, "Well that's okay. I'll hold his hand tighter when I take him outside and teach him to climb trees." In a moment, other family members chimed in with their support.

Not everyone is going to react as supportively as Bob and Marcia's family did. Each person who learns about your baby's visual impairment may respond differently. Some people will say just what you need to hear at the time, but others will miss the mark and say something that may upset you. They may tell you that it was meant to be, that you've been "chosen," or that they're sorry for this "tragedy."

Whether you're talking with family, friends, or complete strangers, there will be times when you'll be uncomfortable, confused, or angry at people's reactions. You may get advice or questions you don't want, hear stories about other people with disabilities, and receive empathetic pats on the back. Try to remember that most people have little or no experience with vision loss and so they're not sure how to react to you or your child.

Your Child, Your Message

Most people will follow your example about how to treat your child and the topic of his visual impairment, so think about the message you want to give them about your baby.

- **Give the facts:** Tell people the name of your baby's eye condition and how it affects how he sees. Depending on your relationship and how much information you want to share, you can also tell them what you've learned about raising a child who has a visual impairment. You might want to share the FamilyConnect web site address with them so they learn more about visual impairment.
- **Let people know what you want from them.** Tell them what your baby needs. If you want them to treat your son the same as they treat other children his age, tell them. If you want them to understand how to interact with a visually impaired child, ask them to talk to your son and explain what they're doing. For example, they need to let him know that they're going to pick him up or try to hug him before they do so.

- **Share what you need too:** If you want a friend to just listen, tell the person you're not asking for advice, just a sympathetic ear. If you want some time to yourself to work through difficult feelings, let family and friends know that having them watch your kids for an occasional afternoon would be a big help. No one is a mind reader, so it's important to communicate clearly about what you and your baby need.
- **Share what you don't need:** If you don't need advice or don't want to hear stories about medical miracles that happened to other families, let others know.

Some people may think that when you tell them about your baby's visual impairment, you're asking them to help fix the problem. Explain that your baby's vision loss probably can't be "fixed" with eyeglasses or surgery. But your baby can learn to use whatever vision he has, plus his other senses, and become just about anything he wants to be.

Though it may be difficult at times to maintain, a positive attitude can help make life better for you and your baby. Don't focus on what your child can't do; instead, concentrate on what he can do. You can help others do the same by sharing your baby's successes with them.

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FamilyConnect is an online, multimedia community created by the American Foundation for the Blind (AFB) and the National Association for Parents of Children with Visual Impairments (NAPVI). This site gives parents of visually impaired children a place to support each other, share stories and concerns, and link to local resources. The site also features a mom-authored blog, inspiring video testimonials from families, and articles authored by parents and experts in the field of blindness on multiple disabilities, technology, education, and more. From the personal to the professional, families will find all the resources they need to raise their children from birth to adulthood.

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