

Caring for Family

You can manage life on this new road.

Your baby or child has received a diagnosis of deafblindness. You are learning more about this new reality every day. It's true there is a lot to learn about your child's condition and the services available to help with it. But, you don't need to learn everything at once. Looking too far down the road at this point can be overwhelming. It can leave you feeling "out of gas" to deal with everyday life at home.

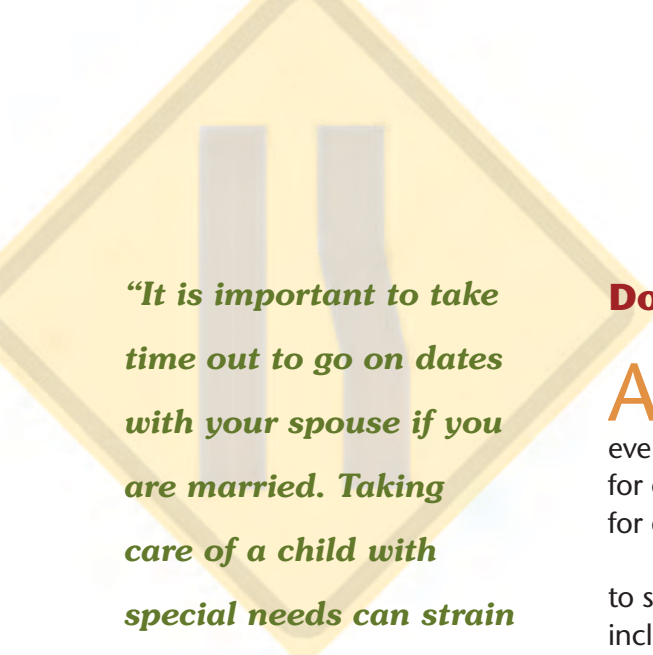
Throughout this Road Map we've given you insights from parents and families who have traveled this road before you. We hope to do the same here. We all have seen and felt the stress on family life when there is a child with special needs involved. We also have found ways to manage that stress.

Just as your child's situation is unique within the deafblind world, the ways you manage stress will be unique to you and your family. This is a situation where one size does not fit all. As you read this advice from experienced families, you may find ideas that fit your current needs and glean ideas to support you as you move forward on your journey.

"When your child is first diagnosed deafblind, give yourself time to grieve.

You are grieving the loss of dreams. One day, life will seem manageable and okay again."





“It is important to take time out to go on dates with your spouse if you are married. Taking care of a child with special needs can strain a marriage. It’s also important to give yourself time, even just five to ten minutes a day—you need to take a breather.”

“I sometimes look back wistfully at the time in my life when I was inconspicuous—before we used sign language, before there was a guide dog in the family. It was nice to just blend in. This is not an option any longer when we go places as a family. There are times when I just want to stare right back at those who stare at us. Thankfully, I usually am able to either ignore them or look back with a smile.”

Don’t travel alone.

As we’ve traveled this road, we’ve come to recognize the importance of taking care of ourselves—the primary caregivers—even while we take care of those we love. We must take time to care for our own physical and emotional needs in order to be able to care for others’ needs.

One of the most important ways you can take care of yourself is to seek others’ support. This support can come in many forms, including support groups that focus on your child’s specific etiology, professional counseling, and support from families that also have a child who is deafblind.

Many parents find that their friends who have typically developing children cannot relate to the unique development of a child who has combined vision and hearing losses. Connecting with parents who are on this same path provides an outlet for celebrating successes as well as frustrations. Plus, you can pick up knowledge from other parents that reduces your learning curve on many deafblind issues.

There may be points along this road where you or another family member could benefit from professional counseling. A trained professional can help with personal, sibling, or marriage issues. Your physician or your child’s doctor can refer you to appropriate service providers.

“In the beginning, we were overwhelmed by information, especially while caring for our baby. We asked my sister to sort through the volumes of information and share the condensed version with us. We filed away the ‘volumes’ for reference when we need specific information.”

“When Andy was young, I wished for a crystal ball so I could look into his future. Now that he’s older, I realize how rewarding it has been having him in our lives. He has helped us realize what is really important in life: a loving family. We have learned not to impose our concept of success on him. Andy is happy with his independent life. We know he will face challenges and frustrations in the future. But, we hope the foundation of love, self-confidence, and support he has will help him continue to experience a productive, rewarding life.”

Pace yourself for the long haul.

This is a marathon, not a sprint; a journey, not a destination. In other words, don't wear yourself out. Learn to say "yes" when help is offered. A ready-made meal or an offer to take a sibling on a play date can provide the break you need to make it through the day.

Keep a list where you jot down things you run across in your day that you could use help with. That way you will have specific jobs ready when someone offers to help with "whatever you need." Remember that most people who offer to help truly want to make your life easier. They know they cannot change your child's disability, but they can help relieve some of the demands on your time. When you accept their help, you are giving them a chance to feel valued. Your acceptance is a gift to them, just as their offer is a gift to you.

If you don't have family and friends offering to help (or even if you do), consider respite care offered through your county social services. Respite care can be a lifeboat to keep your family afloat. Children who are deafblind require an enormous amount of hands-on instruction since they miss incidental learning due to their sensory deficits. For caregivers, this constant state of being "on" is both emotionally and physically draining. Respite care for a few hours or an entire weekend can recharge your batteries.

You can also feel energized when you take time every day to do something for yourself. A walk outdoors, a few minutes of quiet time with a cup of tea and a good book, or a few extra minutes in bed can do wonders to clear your head and help you find joy in each day. Also, schedule regular check-ups for yourself, just as you do for your child. Prolonged stress is a threat to your well-being. Addressing it with your physician is the first step in learning to relieve or minimize the stress in your busy life.

A note about holidays:

Holidays and family get-togethers can be challenging for a family with a deafblind child. Since many of our children require daily routines to allow them to anticipate what is to happen next, anything out of the ordinary can set off fears and unwanted behaviors. Besides the change in scenery, the child may be surrounded by others who cannot communicate with him or her. We have had to adjust our expectations for these times. That might mean going to events for just a short time, hosting events at our homes so that our kids feel comfortable, or having a sitter stay with the child while the rest of the family attends an event.

"For me, the key to achieving balance in life is to break things down into manageable pieces—and then have someone else take care of some of those pieces!"



“It is an eye-opener to realize that, as much of an impact as we parents believe we have on our children who are deafblind, the reality is that in most cases their brothers and sisters will live longer with them than we will. We cannot control what will happen to these relationships after we are gone. But, we can do our best now to foster strong relationships between everyone in the family.”

Siblings need special care, too.

Your other children might feel their world has turned on end with the arrival of a sibling who is deafblind. They might feel that the disability is their fault and/or simply miss time spent with you. Some families set up a regularly scheduled “date” with each sibling, providing individual attention for each child. Dates can range from an afternoon or evening out somewhere, or simply ten or fifteen minutes of story or game time. If your deafblind child’s medical needs prevent you from leaving home, “date time” can be arranged when your medically involved child is napping.

Siblings of children who have special needs bear their own type of “battle scars.” It can help them understand what they are living through if they have the chance to connect with other children who are traveling the same road. ARC of Minnesota offers sibling support groups to encourage these connections. Contact your local ARC chapter to find out when these are scheduled, or if pressed for time (a real possibility!) add this to your list of things others can take care of for you. Then someone who’s offered to help can make the call. To find a local ARC chapter online go to www.thearcofminnesota.org or call 651-523-0823 or 1-800-582-5256.

“We have always wondered about the effects our special needs child has on his siblings and will it drive them to therapy or make them more accepting of society.

Last year there was another boy in our son’s school who had Down Syndrome and vision

problems. One of my daughters pointed out how our son looked so much like the boy. I launched into what I thought was a very detailed explanation of the characteristics of Down Syndrome. At the end of my ‘speech’ my daughter looked at me bewildered and said, ‘I meant they both have blond hair and glasses.’”



“As we all know, having a child who is deafblind changes life for everyone in the family, especially for sisters and brothers. I have worried about how our ‘typical’ daughter is impacted. Will she need years of therapy to deal with these issues? Will she go running from our home as soon as she has her high school diploma in hand?”

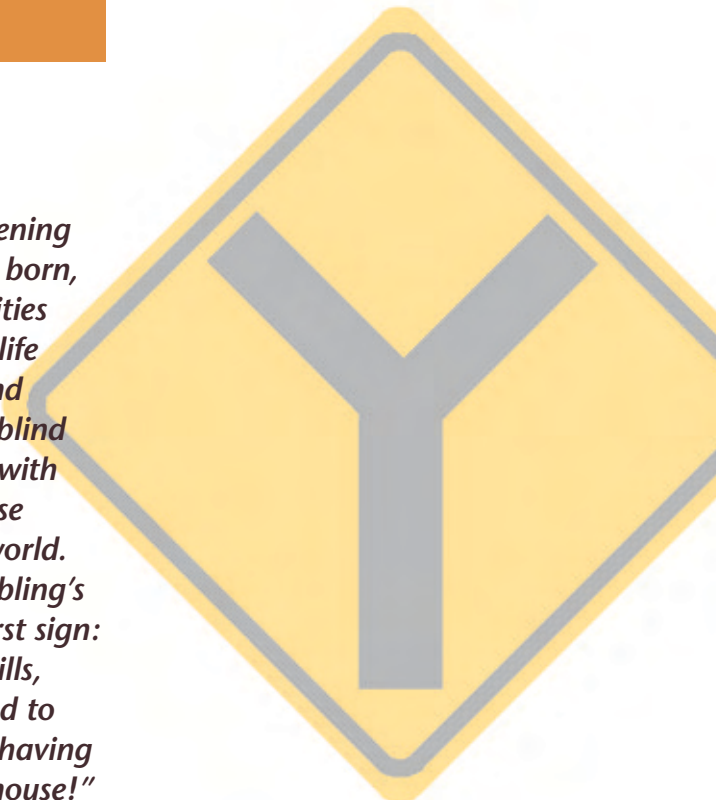
Now that our daughter is old enough, I signed her up for a sib shop—a support group for siblings of kids who have special needs. I wasn’t sure how she would like it. After the first meeting, I peppered her with questions about what it was like. I received mostly monosyllabic responses. I felt a little frustrated and not sure if it was going to be a worthwhile effort. Later, I saw that my daughter had written in big letters ‘SIBSHOP’ on the calendar for all the upcoming meetings. That was all I needed to know.”

“My son gets more attention because he has more needs than my daughter. She was so patient and good, but I could tell that her spirit was deflating. Now, I make it a point to do something just with her. This one-on-one time recharges her.”

One sibling’s view:

“Having a sister who is deafblind has been an eye-opening experience for me. I was just nine years old when she was born, so I didn’t fully understand the implications of her disabilities at the time, but as I grew older I was able to see how my life changed when Emily entered it. For me, having a deafblind sister meant taking sign language classes, attending deafblind family retreats, and being exposed to many other people with disabilities. It was overwhelming, but I’m thankful for these experiences because they changed the way I look at the world.

Many big sisters might excitedly relate tales of their sibling’s first word; I, however, will always remember my sister’s first sign: ‘more.’ Because of her, I now have rudimentary signing skills, I know how to use a TTY, and I’ve even become acclimated to having captions on the television. One thing I love about having a sister who is deafblind—it’s never a boring day at our house!”



“When our son was 5, he got glasses to see better and tubes to facilitate better hearing—hopefully speech would follow. Neither happened, and we had to accept that quick fixes would not be a part of our lives. But after six years of trying our little guy can finally put on his own socks, which shows sometimes success comes to those who take the hard road and just keep trying.”



“I think my breaking point was when Samuel was in his first week in the NICU (neonatal intensive care unit) and undergoing his first major surgery. I was nervous and trying to heal from surgery myself. When I saw Samuel being rolled down the hall by his doctor, my heart felt like it was going to come out of my chest. As I watched him roll by, I knew that I could not look at him, not this way. My sweet baby had bars on his face called a jaw distraction. My friend noticed the expression on my face as I made my husband go see Sam first. She said the most profound words, ‘It’s okay to not be okay.’ I let go and began to weep. I had been trying with all my might to hold it together and be the strong one. With her help, I realized I don’t have to—it’s okay to not be okay.”

Take care in difficult times.

Sometimes it seems as though the road you’re traveling is off the map. How can you know where to turn when the road becomes really rough? At difficult times, such as when caring for a medically fragile child, seeking the support of families that share this deafblind connection can be invaluable. In sharing time with these families, you will find a safe haven to talk about your child’s diagnosis, work through the loss of abilities as your child’s health declines, or find support for your other children. The people you choose to surround yourself with should be those who acknowledge and accept your feelings as valid—even those mixed feelings of grief and relief for both your child and you if your child’s life comes to an end. We’re on this road together. We can help each other along the way.

“When your child has a terminal condition, there may come a time when you must come to the realization that there is nothing more that you can do. You need to keep in mind quality of life issues for your child—not for yourself, but for your child. This could mean letting the inevitable happen. There may be some medical procedures that could extend your child’s life, but at what cost? If the side effects of the procedure would decrease your child’s quality of life, you, as the parent, may need to make the decision that the procedure may not be in your child’s best interest. This is hard to write, but that is the place we are at now.”

Our Contributors

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