



Carle Foundation Hospital  
Expanding Children's Hearing Opportunities (ECHO)

## Coping with the Diagnosis: Parent Views

### *What Are Normal Reactions?*

When we are told that our child is deaf or has a hearing loss, we normally experience a variety of emotions. These emotions may include relief, shock, fear, denial, sadness, grief, confusion, anger, guilt, disbelief, and surprise.

~"When my daughter's hearing loss was finally diagnosed I felt such a sense of relief. That might sound odd, but I was so relieved because despite what her doctor and my friends and family had been telling me, I knew something was wrong. Finally getting a diagnosis meant that we had a place to start. We knew what we were dealing with, and now we could begin to educate ourselves and try to figure out the next step."

~"I cannot remember anything they said after the word "deaf." I had to call the office later and ask for all the details over again."

~"I was surprised to learn she had a hearing loss, and I felt guilty about the possible causes."

~"I was very scared because it was unknown to us. We didn't know what DEAFNESS meant."

~"I was very depressed for awhile."

~"I was devastated and shocked. I remember only being able to go home. I wasn't able to get on with the normal daily activity. I just had to be at home. I was shattered. The first week I cried a lot, and desperately wanted to do everything in my power to make her hear! I had heard about the Cochlear Implant and my initial reaction was that it must be the way to make everything right again."

~"I was relieved that it was ONLY deafness."

~"For me, the hardest part at the beginning was fear of the unknown."

### **Uncomfortable Territory**

Most of us have never had any experience with deafness or hearing loss of any kind, and therefore suddenly find ourselves launched into very unfamiliar and uncomfortable territory. For many, this experience is not unlike the grief process. It is very individual; everyone reacts differently.

### **No Wrong Way to React**

Some parents have little problem accepting the diagnosis and seem to move on without a hitch, while others find themselves struggling to come to terms with it, sometimes for an extended period of time. Regardless of what your reaction is, be assured that it is normal. There is no right or wrong way to react.

<http://deafness.about.com/library/weekly/aa091100a.htm>  
<http://www.kidneeds.com>



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### *Accepting the Diagnosis*

Just as individuals react differently to the news that their child is deaf or hard-of-hearing, acceptance of the diagnosis is also a very individual process.

~"I find acceptance to be an ongoing thing. I have been able to accept that my daughter is deaf and I think I did that fairly soon after the diagnosis. It is something that never goes away because some new challenge always pops up to remind me all over again."

~"I have a problem with the word acceptance. At what degree can you accept that your child has limitation in communication with other people?"

~"After a short period, I accepted the hearing loss pretty well. During that time, I got every book on childhood hearing loss that I could find in the library. My goal was not that he will learn to read, but that he will not graduate with a lower reading level. I think the deafness was easier to accept for two reasons...we knew it was a very real possibility, due to the meningitis and that he was so sick that he almost did not survive. Given that, a deaf child is no big deal."

~"At first I would wake up in the morning, and then I would suddenly remember. "Oh yeah, he's deaf, and I would feel sick. I still remember that feeling, although it did not last long."

### **An Ongoing Process**

Most parents describe acceptance as an ongoing process, one that comes and goes over time. When talking about acceptance, we are not just talking about accepting the hearing loss itself. We are also talking about the acceptance that life as we knew it has changed. Initially it feels like everything has changed.

Over time, we become educated and realize that the hearing loss is merely a part of who our children are, not a definition of who they are. We knew how to communicate with our children, and suddenly that has all changed. We had a pretty good idea of where they might attend school and dreamt of the college they would attend and the career they might pursue. Now we have no idea how to even go about educating a deaf child or hard-of-hearing child, or even what options are available, let alone what the future might hold for them.

### **The Good News**

The good news is that we do find acceptance and begin to adjust. Over time, dealing with a hearing loss just becomes a part of our family. It is still a part of our lives, but it is just that...a part of it. It is not the defining factor in our relationship with our child. It becomes comfortable and when we look at our child we no longer see the hearing loss, we see the child.



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## Coping with the Diagnosis: Parent Views *Coping Strategies*

Fear of the unknown is often worse than the reality of the hearing loss. Parents are often given the news that their child has a hearing loss, but are given little in the way of an explanation of what this really means.

~"I needed to understand hearing loss and how the ear was damaged. It took me awhile to find out why it was damaged and where. That was an issue with me because I wanted to understand if someone, including myself, had made a mistake when he was sick with meningitis. I needed to know if something could have prevented his deafness."

~"One of the most valuable things for us was to join a Parent Group. Being able to talk to those who really understood what we were going through helped tremendously. Even more important was being able to see deaf and hard of hearing children older than our own child. We were able to see just how normal they were, and it helped us to realize that she was going to be okay."

~"I had no idea where to begin looking for the information I needed to understand my child's hearing loss. I began checking out every book I could find and presented it to the audiologist with a long list of questions every time I saw him. I wanted to know what she heard, what hearing aids would do to help her, what options we had for communicating with her, etc."

~"We were in the mall and I saw two deaf people signing. I knew no signs and had no idea how I was going to communicate with them. I just knew that I had to connect with someone who understood deafness. Prior to my child's diagnosis I would never have done anything like this, but it is amazing what you will do when you are starved for information and don't know where to find it."

~"Getting involved with other parents was a life saver. Our family and friends were supportive, but they didn't really understand what it was like for us. Being with other families who had a child with a hearing loss helped us relax and find the comfort and understanding that we needed as we struggled to figure out what to do for our child. In this group, hearing loss was normal, not something to be pitied or feared."

### **Making Sense of the Unfamiliar**

For most parents, finding out all we can about our child's hearing loss and what it will mean in terms of language acquisition, communication, family dynamics, education, and social development is the key to coping.

As we take our child from appointment to appointment, we are bombarded with unfamiliar technical and medical terms. We know we need to be asking the right questions, but don't even know what those questions are.

To make sense of it all, many of us turn to libraries, the World Wide Web, or phone books to find agencies that serve the deaf and hard of hearing. Some of us even walk up to complete strangers who are wearing a hearing aid or signing. This quest to educate ourselves is something all parents with a child who is deaf or hard of hearing have in common.





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### *Dealing with the Reaction of Others*

In the midst of having to accept and come to terms with our child's hearing loss, we are also in the position of having to deal with the reaction of family and friends, and sometimes the community we live in. Just as each of us reacts differently, there is no way to predict how those closest to us will react.

~"Our family cried. People were sad, and to an extent, annoying. Many would clap their hands and do their own "hearing tests" or give unwanted advice."

~"My family has always been close by and we have always been close. They supported us emotionally."

~"The biggest mistake I made with my family was to cry all of my tears before I called them to give them the news. I knew my parents would be upset by the news, so I wanted to protect them by acting as if everything was fine. Because I was so in control and seemed to be handling it so well, they assumed that I was fine. If I had been honest with them and let them know how devastated I was, they would have been much more able to support me when I really needed it."

~"People were mostly sympathetic toward us. Most people didn't offer too much, but those who "knew someone who knew someone" put us in touch with a few other parents of children with a hearing loss."

~"Many people announced that they would learn to sign, but no one really did."

~"My parents were very supportive and understanding. My mom said, "So we have a special little girl." That was precious. Many of our friends and family, including my brothers and a good friend, made an effort to communicate with our daughter. However, others really didn't understand what we were going through, how to help, or how to react."

### **How Grandparents React**

An important thing to remember with Grandparents is that not only are they sad for your child, they are sad for you as well. Just as we want to make everything right for our children, they want to do the same for us. They feel helpless and often go through their own time of grieving.

While most want to be able to support you through this time, realize that they themselves may be having a difficult time of accepting the news that their precious grandchild has a hearing loss. Seeing your child wearing a hearing aid or the thought of trying to learn a new language to communicate with their grandchild (if sign language is the chosen method of communication) may be very difficult for them. Just as you need time to adjust and adapt to the changes in your life, they too need time.



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### *Where to Find the Information You Need*

There are many ways to find information that will educate you about your child's hearing loss, as well as how to cope with that loss.

### **Information on Understanding Your Child's Hearing Loss**

The following links will help you locate information about your child's hearing loss and many of the terms associated with it.

Link to [All About Hearing Loss](#)

[American Society for Deaf Children Fact Sheets](#)

<http://www.boystownhospital.org/parents/info/index.asp> <http://www.nichcy.org> (click on "Publications")

<http://www.handsandvoices.org> (Click on "Articles Index" at bottom of page)

### **Information on Finding Support from Other Parents:**

We often feel very alone. Most of us do not know anyone else who has a child with a hearing loss, and we feel the need to communicate with others in the same situation. Being able to connect with other parents who share this experience can be invaluable. There are local, statewide, and national parent organizations that parents can tie into. Unfortunately, they are not available in every city and state, but because of internet access, parents all over the United States and the world are able to connect, as well as offer support. The following sites are just a sampling of the many sites available:

<http://www.deafchildren.org>

<http://listen-up.org>

<http://www.saywhatclub.com>

<http://www.shhh.org>

<http://www.parenttoparent.org>

<http://www.gohear.org>

<http://www.nichcy.org>

### **Information on Deaf Culture and Community**

Soon after being told that our child is deaf, many of us are told that there is something called "Deaf Culture," or "Deaf Community." The idea of our child becoming part of a culture or community that is foreign to us is frightening. Understanding what is meant by these terms can be very helpful. We discover that there is a rich culture that our child may someday choose to be a part of. It is nothing to be feared.

Deaf and hard of hearing adults can be a wonderful source of information and education, as well as provide support in raising our children. Most are willing to share their knowledge and personal experiences with us and welcome questions from parents who are striving to make the best decisions possible for their children. Below you will find links to web sites that will connect you to these individuals.

<http://www.nidcd.nih.gov>

<http://www.gallaudet.edu>

<http://www.nad.org>

<http://www.aslinfo.com>

<http://www.deaflibrary.org>

<http://www.deaflife.com>