A Family Affair
Grandparenting a Child Who Is Deaf or Hard of Hearing

By Krystyann Krywko, Ed.D.

“One of the hardest things about having a grandchild with special needs is knowing when to help, when to say something, and when to keep quiet,” says Charlotte Thompson, M.D., in her book, Grandparenting a Child with Special Needs. The news that a child is deaf or hard of hearing (DHH) can be a stressful time for families, especially when there is no experience with adults or other children who are DHH. During this time, relationships and family dynamics can be put to the test.

“I’ve yet to find a grandparent who didn’t want to help or for that matter a family that did not need help,” says David Luterman, Ed.D., CCC-SLP, professor emeritus at Emerson College in Boston, Mass., and an expert on counseling parents of children with hearing loss. “The solution is often in helping the family communicate their needs better within an emotionally safe environment.”

As a grandparent, you have a unique role to play and—depending on time, resources, and distance—the support you can offer ranges from emotional to financial, to becoming the “go-to” person when the pressures of appointments, therapy sessions and everyday life becomes too much for the parents. While every family is unique in how they will respond to the new reality of having a child who is DHH, the strategies below can help ease the transition.

Where Does a Grandparent Fit in After a Diagnosis?

Grandparents are often removed geographically from families and this can make it difficult for them to feel connected to the immediate emotions and decisions that are made surrounding a diagnosis. In addition, they might also miss the day-to-day successes and frustrations as their grandchild progresses.

In the early stages after a diagnosis of hearing loss, parents may not have accepted the diagnosis themselves and are unsure how to involve, or talk to, grandparents. Grandparents are often just as anxious and confused about the diagnosis and what the future might hold for their grandchild.

“Grandparents are a very important part of each child’s team,” says Dorene Watkins, M.Ed., school psychologist at the Center for Hearing and Communication in New York City, “and we really try to include them in all aspects of their grandchild’s services. We have grandparents that volunteer at the office, attend their grandchild’s speech therapy sessions, and who speak with me for family counseling.”

As a grandparent, try your best to remain in the information loop during the early stages of diagnosis. Ask your son or daughter to send you weekly emails, forward website referrals he/she may have received from professionals, photocopy articles or send brochures. In this way, you are sending a message that you are there for the family and want to keep involved in the process.

“I knew something wasn’t right with my grandson’s hearing,” says Roxanne, grandmother of Douglas who wears bilateral hearing aids, “and was actually relieved when he was finally diagnosed. There was a tremendous amount of uncertainty and worry about his development and it was difficult at first, but I give so much
credit to my daughter who made sure that I remained involved in his progress even though we live so far apart.”

**Grieving as a Grandparent**

As a grandparent, it is important to work through your own grief process. It can be hard to talk about your feelings with your child—who is a parent now—as you don’t want to overload them at a time when they are most likely dealing with their own feelings.

“The diagnosis can be a double whammy for grandparents, as they are grieving for both their child and grandchild, and it takes time,” says Watkins.

“All four grandparents grieved for us and with us,” says Christina Danese, mother of Jack, a 16-year-old with bilateral cochlear implants, “but all went into action immediately, contacting their network of friends for information and resources.”

Finding out your grandchild is DHH can be an emotionally isolating experience. Parents can find support groups or online communities, but there are not that many groups designed specifically for grandparents of children who are DHH. Instead of being referred to a support group by an audiologist or therapist, grandparents often need to take things into their own hands and create a customized support network.

“I have many grandparents who contact me,” says Michelle Kraskin, Au.D., audiology supervisor at Weill Cornell Medical College in New York City, “and in many ways I prefer giving the grandparents the information firsthand. Doing this takes a lot of the burden off of the grieving parent, plus it lets the grandparents feel that they, too, are taking an active role in their grandchild’s well-being.”

**Stay Positive**

Despite what you might be feeling, it is important to keep a positive attitude for both your child and your grandchild. This is especially important during the early stages of a diagnosis when everyone is still trying to figure out next steps.

When my son was first diagnosed with late onset hearing loss, my mom was the first person I reached out to once we had a confirmed diagnosis. I called her from the back seat of the taxicab as we sped away from the audiologist’s office. I was close to tears, as I repeated newly acquired terminology like “bilateral,” “sensorineural,” “permanent hearing loss,” and “hearing aids.” My mother’s response: “That’s so great, honey. Now that you have figured it out, Henry will get the help he needs.”

My mother later confided that while she meant those words when she said them, she was still very unsure at that point what exactly the future would hold for Henry. But as I look back, my mother’s response helped shift my focus from feeling sorry for myself and for my son, to a position of strength so I could focus on getting Henry the help he needed.

**Family Ties**

Much of the support you will be able to offer as a grandparent depends on family dynamics. Based on my own experience if you have a close relationship with your child and son- or daughter-in-law, it can be easier to continue communicating along the same lines.

However, if any of the relationships were strained prior to the diagnosis, then there might be a little more work to be done in repairing those relationships before the family is ready to move on. “Any kind of a diagnosis will bring a family closer together, or move them further apart,” says Luterman.

There are really two relationships involved in the situation: the relationship you have with your child and the relationship you have with your grandchild. Sometimes you will need to let go of past difficulties and focus on the needs of your grandchild. Be open to suggestions and don’t view advice from the parents as criticism.

“When my daughter received her first pair of hearing aids at 13 months, it was an adjustment for everyone,” says Linda Dolce, mother of 4-year-old Valentina who wears bilateral hearing aids. “I had to show our parents how to hold her so she wouldn’t get feedback from the aids. I also needed to be patient and explain to them over and over again how important it was for Valentina to wear her hearing aids.”

**Become Informed**

Many grandparents grew up with a much different public
perception of people who are deaf and hard of hearing. Children who are DHH have a very different experience today compared to children 30 or 40 years ago. Early intervention, technology and access to education have all changed exponentially for the better over the years, which has led to dramatically different social and educational outcomes for today’s children who are DHH.

It is difficult to offer support to your child and grandchild if you don’t understand what their needs are. Additionally, gaining a better understanding of what it means to be DHH today can help you sort out your emotions and help you feel more involved.

“At first, we were heartbroken,” says Nancy Sanborn, mother to Christina Danese, and grandmother to Jack, “but we met with experts and observed other youngsters who were DHH. Speaking with psychologists, teachers, audiologists and speech-language pathologists helped us to reconcile the fact that being DHH would not be insurmountable for our grandson.”

In order to understand educational opportunities, technologies and services that are available for your grandchild who is DHH, it is important to connect with reliable resources. You can either find referrals to information from your child or you can find these resources yourself. There is a great deal of information on the internet, although it is important to “Google” responsibly. Connect with professionals and organizations that can lead you to trustworthy resources. The AG Bell Listening and Spoken Language Knowledge Center (ListeningandSpokenLanguage.org) is a great place to start.

Interacting with Your Grandchild

When your grandchild has special needs it is easy to get caught up in the everyday issues and challenges, not to mention doctor’s appointments and therapy sessions. Despite all these “extras” your grandchild who is DHH has the same need for love, attention and fun that your other grandchildren have.

There are some accommodations you will need to learn how to make to support the needs of your grandchild (such as adjusting how you communicate, dealing with noisy restaurants, using captioning and arranging seating at the holiday dinner table) but overall you don’t need to treat your grandchild any differently.

Don’t change expectations or responsibilities. Talk to your grandchild. Use single- and multi-syllable words. Read books. Tell stories. Sing songs. Cook together. Look for positive aspects and celebrate even the smallest accomplishments. These are also ways in which you can give your grandchild the gift of language.

“In the end, grandparents are either part of the team or part of the problem,” says Watkins. “Over the past 30 years of professional practice, I have been exposed to numerous family dynamics and it is the grandparents who choose to provide emotional support that really make a difference.”

Tips for Grandparents

- Become involved: many hearing loss organizations include grandparents in family programs and fundraising efforts. Join events in your community, or where your grandchild lives.
- Be there: offer your support to your child but don’t force it. Think about what you would have needed or liked to have done in a similar situation.
- Give space: family members will move through the grief process at different rates. Remember to give each other space.
- Be proactive: professionals might not think about including grandparents in the process. Ask your child if it would be okay if you phoned or emailed professionals on your grandchild’s team with any questions you might have.
- Become tech savvy: learn how to use and care for your grandchild’s hearing aids and/or cochlear implants.
- Catch yourself: pay attention to what you say to your child or grandchild; offhand, negative remarks can have a lasting impact.
- Look past the diagnosis: your grandchild is a unique individual; help them build their strengths and support their weaknesses.

Resources

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