



Reaching Out to Moms and Dads

When learning the diagnosis of their child's hearing loss, whether the child is 3 months or 6 years of age, parents respond in different and often unexpected ways. As professionals, we've learned about the stages of grieving and denial parents experience. We gather printed materials, Web site addresses and early intervention contacts to share with families. We have our OAE and ABR results and our trusty "familiar sounds" audiogram. But where do we start, what do we say?

English, Kooper and Bratt (2004) have suggested guidelines for audiologists in "Breaking Bad News," based on guidelines developed by the medical profession.¹ Bad news need not be perceived only at the time of diagnosis; it can also involve a change in hearing, poor performance with amplification or even identification of a conductive loss requiring surgical intervention.

Guidelines for breaking bad news:

1. The diagnosis should be given by the audiologist who administered the tests and/or will be managing the child's aural habilitation.
2. Ensure privacy and adequate time, with no interruptions.
3. Assess parents' understanding of the situation.
4. Encourage parents to express feelings.
5. Respond with warmth and empathy.
6. Give parents a broad time frame for future decisions and actions.
7. Provide parents with concrete activities to engage in while waiting for the follow-up appointment.
8. Arrange a follow-up appointment.
9. At the follow-up appointment—review, expand and initiate aural habilitation.
10. Document and track the information and counseling support provided.¹

When parents are faced with the purchase of their first (and subsequent) set of hearing instruments, the cost can be one of many overwhelming issues. Doesn't my insurance cover

these? How can we afford them? Where do we apply for assistance? Is there a payment plan? We must be familiar with the resources available to parents to make hearing aids accessible as quickly as possible, even while waiting for funding decisions. Some large pediatric audiology facilities—and some hearing aid manufacturers—may offer loaner bank instruments in these situations.

Each state is mandated to have an agency that coordinates early hearing detection and intervention (EHDI) services for children with hearing loss; your state's EHDI contacts can be found at www.infanthearing.org. For a comprehensive list of all resources available to children and young adults in your state with hearing loss, visit the National Dissemination Center for Children with Disabilities at www.nichcy.org/Pages/StateSpecificInfo.aspx. Other sources of assistance: SERTOMA, Lions, QUOTA (www.wesharefoundation.org), AUDIENT (www.audientalliance.org), and the HIKE Fund (www.thehikefund.org).

Parent networks can help parents share emotions, fears, experiences, and perhaps gain strength and an accessible phone resource for distressing moments. Some states have established parent-to-parent networks; Hands and Voices has developed a formalized, parent-led support program, Guide By Your Side™ (www.handsandvoices.org) "that provides emotional support and unbiased information from trained Parent Guides to other families and to the systems that serve them." Eleven states have either established or are starting up GBYS programs.

Support for dads, who are often unable to join or uncomfortable with mom-focused support groups, is also important. The National Fathers Network (www.fathersnetwork.org) is a nonprofit organization that supports fathers and families of children with special needs and provides resources for educators and health-care providers. Its mission states, "Providing 'father friendly' medical and educational services positively impacts all family members. Isolation is reduced, self-esteem is enhanced, and caretaking roles are shared."

Parents are busy being parents first and foremost. Parents of children with hearing loss are busy being parents, too, compounded by daily concerns about their child's development, hearing aids, speech and language, education and future success. There is no one right way when it comes to counseling or advising families and children with hearing loss. We must, however, treat each family with respect, honor their racial, ethnic, cultural, and socioeconomic diversity, listen to their individual needs, and offer knowledgeable support. \$

REFERENCES

1. English, K, Kooper, R, & Bratt, G. (2004). Informing parents of their child's hearing loss: "Breaking bad news" guidelines for audiologists. *Audiology Today*, 16(2), 10-12.

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