SUPPORTING FAMILIES OF CHILDREN WITH USHER SYNDROME: Information for Educators

QUICK FACTS ABOUT USHER SYNDROME

- Children with Usher syndrome are born deaf or hard of hearing or gradually lose their hearing.
- Progressive vision loss is caused by retinitis pigmentosa, causing night blindness and tunnel vision.
- Vestibular dysfunction is associated with Usher Types 1 and 3.
- Children with Usher syndrome have typical intellectual abilities.
- Usher syndrome is inherited.

For more information, visit **Identification of Usher Syndrome: Information and Resources.**

Role of Educators

Educators are often the first people to notice that a child who is deaf or hard of hearing is struggling with their vision or balance. This may manifest as a child who is clumsy or accident prone. These behaviors may be caused by vision loss associated with Usher syndrome and require further assessment by healthcare professionals.

If a child is suspected of or diagnosed with Usher syndrome, be prepared to support the family with compassion and resources.

Talking with Families

- Because timelines for vision loss are hard to predict, be cautious about sharing specific expectations with parents. Typically, children with Usher Type 1 have vision loss in the first decade of life, while vision loss for those with Type 2 and Type 3 manifests in the second decade, but the progression can differ from person to person.
- Refer the family to a genetics counselor who can explain the benefits of genetic testing for their child. Share information, such as **"A Parent's Guide to Genetics and Hearing Loss" from the CDC** and resources specific to your state.
- Be sensitive to the way you describe the diagnosis. The term "deafblind" can be disconcerting, particularly when a young child is not yet exhibiting signs of functional vision or hearing loss. Explain that the term refers to varying degrees of loss that differ from person to person.
- Parents may seek your help to consider the impact of choosing when and how to disclose the diagnosis to the child.

Family Perspectives

- When a child is suspected of having Usher syndrome, every parent and family responds differently. They may be overwhelmed, in shock, or in denial.
- If a family wishes to pursue genetic testing, share resources and referrals.
- Cultural norms may preclude a family from accepting or revealing their child's diagnosis.
- If parents choose to share the diagnosis with their child, help them find language to match the child's intellectual and emotional level (see "Usher Syndrome: From Their Perspective" under Family Resources).
- Sometimes parents have concerns that a sibling who is deaf or hard of hearing may also have Usher or that siblings might be genetic carriers. Share resources and referrals to help them learn more.
- Parents may have assumptions about what people with Usher syndrome can and cannot do. Offer to connect them with other parents, or adults with Usher syndrome, who can serve as positive role models.

Family Resources

Many resources are available to share with families and to help you better understand their experiences.

- The **Usher Syndrome Coalition**, including their **Just for Parents** section
- Your **state deaf-blind project**, to obtain information and resources
- **"Usher Syndrome: From Their Perspective"** (interviews about receiving a diagnosis of Usher syndrome from the parent's perspective and the child's)
- **The Usher Syndrome Society**, including their **Sense Stories** (video stories of people who have Usher Syndrome)
- **Ava's Voice**, including their **educational resources** and monthly family calls

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