

Driving with Usher Syndrome

HELPING TEENS NAVIGATE LIFE IS DIFFICULT ENOUGH, SO WHEN THE EXTRA CHALLENGE OF USHER SYNDROME EXISTS, IT'S ESSENTIAL TO UNDERSTAND THE UNIQUE CONSIDERATIONS SURROUNDING DRIVING AND TRANSPORTATION.

Understanding the Licensing Process

In accordance with Austroads guidelines, individuals with conditions affecting vision, including Usher syndrome, are required to disclose their condition when applying for a driver's license from their state authority, such as VicRoads in Victoria or the Department of Transport in Western Australia.

Disclosing the condition will trigger a medical review process, where the individual will be required to undergo assessment by an Ophthalmologist or Optometrist. These specialists will conduct tests based on the Austroads Fitness to Drive (AFTD) guidelines to assess the individual's vision and overall fitness to drive.

Navigating the Process Together

When broaching the subject of driving with teenagers who have Usher syndrome, it's essential for parents to approach the conversation with sensitivity and understanding. As you and your teen navigate the process of considering applying for a driver's license, it's important to stay informed about the guidelines and procedures outlined by Austroads and your state authority. Maintain open communication with healthcare professionals to ensure that your teen's vision is regularly monitored and any changes are addressed promptly.

Here are some recommendations for discussing driving with teens who have Usher syndrome:

Provide Information: Begin by educating your teen about Usher syndrome and its implications, including the progressive nature of the condition and its impact on vision, balance, and hearing. Help them understand the potential challenges associated with driving, such as decreased night vision and peripheral vision loss.

Outcome of Medical Review

Based on the report provided by the Ophthalmologist or Optometrist, the driving authority will make a decision regarding the individual's eligibility for a driver's license. This decision may include granting a license with specific conditions, such as wearing glasses or refraining from nighttime driving, or denying the issuance of a license altogether.

Ongoing Vision Monitoring

There are currently no specific guidelines on how frequently individuals with retinitis pigmentosa (RP) or similar conditions should undergo vision rechecks. The frequency of vision monitoring is typically determined on a case-by-case basis, guided by the individual's needs and recommendations from healthcare professionals.

Discuss Safety Concerns: Emphasise the importance of safety for both the teen with Usher syndrome and others on the road. Highlight the potential risks and dangers associated with driving with limited vision, including difficulty in detecting obstacles, pedestrians, and other vehicles.

Encourage Open Communication: Create a supportive environment where your teen feels comfortable discussing their concerns and feelings about driving. Encourage them to ask questions and express any anxieties they may have about relinquishing the idea of driving.

Explore Alternative Transportation Options: Explore alternative transportation options that can help your teen maintain independence and mobility without compromising safety. This could include public transportation, ridesharing services, walking, biking, or relying on family and friends for transportation.

Discuss Adaptive Technologies: Explore adaptive technologies and resources that can help individuals with visual impairments navigate their surroundings more safely. This may include talking about assistive devices, mobility training programs, and orientation and mobility specialists who can provide guidance and support.

Highlight Positive Aspects: While discussing the limitations associated with driving, also emphasise the numerous opportunities and activities your teen can still engage in despite not driving. Encourage them to focus on their strengths, interests, and abilities beyond driving.

Seek Professional Guidance: Consider involving healthcare professionals, vision specialists, or counsellors who have experience working with individuals with Usher syndrome. They can provide valuable insights, guidance, and support tailored to your teen's specific needs and circumstances.

Encourage Independence: Help your teen explore ways to maintain independence and autonomy in their daily lives, even if they are unable to drive. Encourage them to develop problem-solving skills, self-advocacy, and confidence in navigating the world with Usher syndrome.

Ultimately, the decision about driving with Usher syndrome should prioritise safety and well-being while also considering the individual's desires and capabilities. By approaching the topic with empathy, understanding, and open communication, parents can support their teens in making informed decisions about driving and explore alternative avenues for independence and mobility. By understanding the licensing process and advocating for safe and responsible transportation options, you can support your teen in maintaining independence and mobility while prioritising their safety and well-being.

For more information, visit <https://austroads.com.au/publications/assessing-fitness-to-drive/ap-g56/vision-and-eye-disorders/general-assessment-and-management-guidelines>