

What are the risks of swimming for children with vestibular dysfunction in Usher syndrome?

Children with Type 1 Usher syndrome often experience both hearing loss and vestibular dysfunction, which significantly impact their balance and spatial awareness. Additionally, progressive peripheral vision loss due to retinitis pigmentosa (RP) further complicates their ability to navigate and respond to their surroundings. These challenges become especially dangerous in water, where visual and sensory cues are often reduced or distorted.



Blurry vision underwater

Due to peripheral vision loss, children's ability to see objects around them is limited. Underwater, visual clarity is further reduced as light bends and distorts, making it even harder to recognize objects, people, or landmarks. This can lead to disorientation, making it difficult for children to determine their position. As a result, they may panic or make unsafe movements, increasing their risk of danger in the water.

Lack of stable ground contact

With vestibular dysfunction, maintaining balance depends heavily on children's feet and body's contact with the ground. However, in water, body positioning can be difficult to sense. Floating or moving in deeper water further reduces spatial awareness, increasing the risk of losing control or feeling unstable. Sudden movements like jumping into the water, can be especially dangerous, as children may struggle to regain their footing or determine which direction is up.



Hearing loss

Pool environments are often noisy and echo-filled, making it difficult for children to localize sound or understand spoken directions. Underwater, sound becomes muffled, further reducing their ability to hear verbal instructions and safety cues from caregivers. Hearing loss adds to this challenge, making it even harder to rely on auditory guidance. Without clear access to verbal reassurances or safety instructions, children may become panicked, increasing their risk of danger in the water.

How can we support safe swimming experiences for children with Type 1 Usher syndrome?

Teaching the “Mushroom Float” posture

If a child becomes disoriented underwater, they can use the "mushroom" position— putting their chin to chest, bringing their knees to their chest and hugging their legs. This posture automatically helps them float to the surface (with their back rising to the surface first), giving them time to regain orientation. Practicing this technique in safe, controlled environments can build confidence and preparedness. (Watch the technique here: [Water Safety Technique – The Mushroom](#))



Supervised Swimming in Well-Lit, Shallow Water

Always ensure a responsible adult is close by for immediate assistance. Choose well-lit, colourless-water swimming areas to help maximise the child's remaining vision. Additionally, children should swim within their depth to reduce the risk of unexpected loss of balance. The use of goggles may assist to maximise visibility and balance. The use of waterproofing technologies (i.e. Aqua + kits, WaterWear, waterproof hearing aids) to optimise access to sound during water play can also be considered.

Use brightly Coloured or High-Contrast Equipment

Bright swim caps, floatation devices, or pool markers can make it easier for children to see and navigate in the water.

Touch-based or vibrating alerts, such as waterproof vibrating wristbands, vibrating timers, or tactile signals from a caregiver (e.g., gentle taps on the shoulder or arm), can help children receive instructions when verbal cues are difficult to follow.





Teach Auslan Signs Related to Swimming and Water Play

If a child uses Auslan ensure they and their communication partners are taught the signs related to swimming and water activities from an early age.

Ensuring Water Safety for Children with Usher Syndrome

When supporting a child with Type 1 Usher syndrome in water activities, it is essential to consider their unique challenges related to balance, vision, and hearing. Strategies such as choosing well-lit, standing-depth swimming areas, using bright visual markers, using goggles if the child puts their face in the water, providing tactile or vibrating alerts, considering waterproofing technologies, and teaching the "mushroom" posture can help improve safety and confidence in the water. Ensuring close supervision and structured swimming experiences tailored to their needs can make a significant difference.

Swimming is a great activity for all children with Usher syndrome and should be encouraged. With the appropriate support, practice, and motivation they can become excellent/great swimmers.

For further guidance on water safety strategies for children with Usher syndrome, please contact UsherKids Australia at info@usherkidsaustralia.com.