Advocacy and wellbeing

A diagnosis of **Usher syndrome** begins a cycle of continuous adjustment, acceptance and advocacy for the child or young person (CYP) and their family. Many have adjusted to the hearing loss diagnosis, and found a sense of identity and strategies which work. The progressive nature of vision loss associated with Usher syndrome can cause anxiety for the CYP and their family, particularly as they know the CYP is reliant on their vision. They are trying to adjust practically to changing needs and learn the new tools and skills required, as well as adapting emotionally. Usher syndrome can be seen as a hidden disability, so it is vital CYP and families develop the advocacy skills required to ensure they can access the things they want to do. Peer awareness can help support inclusion and development of relationships.

Strategies

- ☐ The child or young person's voice is so important: ask what is helpful to them, and allow them to take ownership of what is shared in training and their one-page profile. Staff can help support development of advocacy skills by asking the CYP what helps them. Some CYP find it less daunting to send an email, after first few weeks of term to let teachers know what is working well, and what isn't.
- ☐ **Peer awareness training** on regular basis (does not have to name or be specific to child, and can address hideen disabilities in general, or sensory loss). This must be planned with the CYP and family, and implemented in accordance with their wishes. Options include; CYP to deliver or support delivery; CYP to be included or not in session; training delivered to peer group/particular chosen CYP/form/year group; sensory support staff to work with the whole class not just the CYP with Usher syndrome.
- ☐ Support the CYP to develop their own '**bank of phrases**' to explain their condition (e.g. “I can see clearly in front of me. My vision is blurry around the edges.”), and the terminology they want to use. With the family’s consent, involve the CYP in conversations with health care professionals so that they have a confident and age-appropriate understanding of their condition, and can describe it in language which works for them.
- ☐ **Boundary setting with peers**. Discuss what they do / don’t feel comfortable sharing with friends, allowing questions to be answered about the condition and helping the CYP decide how they want to let people know if the questions begin to feel too invasive.
- ☐ Give opportunities to meet **peers and role models** who have Usher syndrome / sensory loss, and to access books and media with characters with sensory loss.
- ☐ Give opportunity to act as buddy or mentor to younger kids with sensory loss or additional needs, as well as the chance to submit ideas to SEND CYP forum at the school.
- ☐ Give option of therapeutic avenues such as play therapy or talking therapies, to provide an outlet to talk about their feelings and emotions.

> ***Ensure regular check-ins with parents/family. This diagnosis impacts upon all family members, and the emotional health of wider family will directly affect the wellbeing of the child or young person***

> ***"Having a bank of phrases which I can use to explain my condition has made it so much easier to let new friends know."***
>
> *19 year old*

Key: CYP = Child or young person