

Usher syndrome Type 1

People with Usher Type 1 are born profoundly deaf and cannot hear normal speech even with a hearing aid. Children with Usher 1 have poor balance and may be late in sitting up and walking. Retinitis Pigmentosa seems to develop between 8 - 12 years.

What does this mean?

People are born with a severe to profound hearing loss - which often remains stable throughout their life and is generally not helped by hearing aids. Problems with vision are first noticed at night followed by increasing difficulty with side (peripheral vision). At times this may lead to bumping into or falling over people and objects. People may notice difficulty moving into bright light from a darker place or vice versa. However, they may have adapted to these changes already, particularly in familiar situations.

Is there a cure?

Although there is no treatment available for Usher at the moment, many people with Usher have adjusted very successfully to their condition. Sense is currently conducting research looking into the types of Usher, the genes that are involved and what messages the genes are passing to the cells.

Much can be done to help people make the best use of their vision and hearing.

Communication

Due to profound deafness, learning to speak is not easy and many adults prefer to communicate using [British Sign Language](#) which is a visual language with its own grammar.

People with Type 1 often have strong links with the deaf community.