

Usher syndrome

About Usher syndrome

Usher syndrome is a very challenging disability. People are born deaf or hard of hearing, then gradually start to lose sight in the school years.

But despite the enormous challenges this brings, people with Usher can achieve a great deal. With the right support, many people can go to college, get a job, find a partner and enjoy their leisure - just like anyone else.

The sight loss is caused by an eye condition known as Retinitis Pigmentosa (RP). RP is a disease where the retina slowly degenerates and loses its ability to transmit pictures to the brain. The early symptoms include difficulty seeing in the dark and in different lighting conditions. Over time vision gradually deteriorates until tunnel vision develops.

Usher syndrome is an inherited condition which is passed on genetically by both parents – although they may well not have the symptoms themselves, or be aware that they are carriers of the genes.

Many people do not realise they have Usher until they begin to have problems with their sight. They will have grown up as deaf or partially hearing, and coming to terms with losing their sight as well can be very hard.

But with the right training and support, people with Usher syndrome can be taught to minimise the effects of their new disability. And they can learn new skills which will help them to cope with life when their sight gets worse

Types of Usher syndromes

- [Type 1](#)
- [Type 2](#)
- [Type 3](#)

Support for people with Usher syndrome and their families

Sense provides advice and support to people with Usher and their families - particularly when the condition is first diagnosed. To contact Sense please [click here for our contact details](#).

Is there any treatment available for Usher?

There is no treatment available for Usher at the moment. Sense is currently conducting research looking into the types of Usher, the genes that are involved and where the genes are located.

Usher publications and articles

For further information and factsheets about Usher syndrome please visit our [useful Usher publications page](#).

You can [read Talking Sense articles on about Usher syndrome](#).