



Guidance for parents and families on supporting children and young people with a diagnosis of Usher Syndrome

Everyone with Usher is different and so are their families in the way they receive the news of Usher. Every family will deal with Usher in a different way often because the age of diagnosis will vary as will the extent of the hearing, sight and balance loss. Usher is an uncertain condition and no one can say what will happen in the future so it can help to plan for the positive.

We hope this guide helps you to think about how you, as the expert in your child (or young person), will support them emotionally and practically to understand and adapt to change. We have received feedback from families, people with Usher and from professionals working with families. We hope that you will find something in this guidance which is right for you – but remember if you'd like to discuss your own situation please get in touch with us.

How do parents react to the diagnosis of Usher?

Common reactions to a diagnosis can include

- *It's my fault* - no, it's genetic. You didn't choose your genes and you had no choice
- *It should have been me* - it was not your fault or choice
- *I should have known sooner* - Usher is rare and underdiagnosed by professionals. Genetic testing is not widely available for final confirmation. Traits of Usher, especially sight loss, may not be obvious for many, many years. Change is subtle so even the experts struggle and you would not be expected to be able to diagnose)

Reactions and feelings can change over time - there is no right or wrong way to feel. You had one idea of how things were going to be and it takes time to gather enough knowledge and support from others so that you start to feel positive about the changes which have come about. Usher is genetic so it is no one's fault. Open conversations can be helpful as sharing concerns about now and the future may make it easier for everyone. Some people find Usher easier to accept than others – this doesn't matter, we are all different. Some people may just need more support than others.

Who should tell children and young people?

- As parents you are the most important people for your child. They like and need to learn from their parents or someone they have a close relationship with
- Search for support in telling your child from others eg. school, specialist teacher, Sense, counsellor, friends, medical clinicians.

For further support contact Sense on

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Why should I talk to children and young people about Usher?

- Most people with Usher have said they needed to be told about their condition. Often it comes as a relief as they already knew something was different. If children have an understanding about what is going on it may alleviate their worries and avoid them making their own conclusions or researching on the internet which can be frightening. It is a good idea to encourage communication and opportunity to talk and ask questions. A child who doesn't feel they can talk may feel they could/should not express their concerns in order to protect their parents.
- Being told gives young people the opportunity to understand it and talk about it. They can take ownership and be in control of the changes where possible; developing strategies for communication and mobility
- Children often notice they are different to their peers, including other D/deaf children but sometimes they don't realise they can't see what others see, especially at night. They may have felt clumsy because they were unable to see things or anxious in dark places outside, or inside such as the cinema or dark restaurants
- Although children and young people naturally adapt to changes in their vision the process is easier if they are supported to understand and prepare for any changes. Older children can take part in decisions about their future
- Once children and young people develop a sense that Usher is part of them and they own it they can begin to ask for things for themselves. Learning about Usher helps young people to understand what they can do. If there are activities which may be more difficult they may be better equipped to explain to their friends
- They can receive specialist support at home and school (for mobility, communication and other needs). A good experience in education can help towards future confidence and self-esteem. They may need specialist support and adaptations to be put in place in advance of their changing needs

When is the right time to tell a child or young person?

- Children are often ready to learn BUT parents need to be emotionally ready so immediately after diagnosis may not be the best time. You need time to respect your own feelings before you can confidently tell your child.
- Parents tell us that it helps to learn about Usher first and, for some, contact with other parents who have experienced the diagnosis can be valuable. Sense can support you in reaching others
- Every child is different but sight loss through Usher is mostly a slow progression – it will not happen overnight. Take time for you and your child to talk about it – this may not be a big event but a slow drip feed of information

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- Conversations may naturally occur which present good opportunities to talk about the diagnosis. People have told us about children who have found out incidentally or through circumstances where parents felt forced to disclose the diagnosis. It is better to be prepared and tell your child at a time when you feel ready to do so and in the way you feel is best

How do I tell a child or young person?

- Every child is different – try to think about their age and the way the family normally talks to each other. Families often use meal times to talk. It might be useful to plan ways to include the rest of the family in future especially siblings
- It can be helpful to talk little and often so that the child gets used to the idea and may ask more questions rather than a one off ‘sit down’ event. To be told everything at once can be overwhelming – you don’t have to say it all in one go but focus on day to day information
- Find out what they know already – don’t make assumptions. Ask questions to check their level of understanding
- It is an ongoing process and it is likely that you will need to repeat or revisit information
- Keep communication open – wait for children to ask questions but be there to talk when they want to and make sure they know it is OK to ask.
- Be sensible and realistic but try to keep your humour and positivity
- Sometimes it helps to give an analogy or paint a picture for the child or their sibling. For example, if they like football tell them that when we are playing the first half we have no idea what the end result will be. It is the same with Usher.
- Keep in touch with someone who can answer your questions about Usher
- Give thought to who you tell about your child’s Usher and whether this is in confidence – parents have advised that well-meaning friends, wider family or non-teaching school staff may inadvertently talk in front of the child or the child’s friends. People need to be able to respect your wishes about how you want to handle this information with your child
- Also give thought to what you say to brothers and sisters – depending on age do not expect them to ‘keep secrets’ but acknowledge that their sibling may need extra support or understanding

What should I say to a child or young person?

- Learn everything you can about Usher before talking to your child about it. Information can come from professionals (medical, education, social care), family support groups, conferences, information leaflets, recognised research papers and the internet (taking care the source is reputable)

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- Ensure that what you tell them is age appropriate. For example, you may say to a young child that they have an eye problem which means they aren't able to see so well to the sides or up and down or in the dark. An older child may like to search for information with you.
- Recognise that vision is likely to change and so talking about this and what might happen is a realistic and honest way to inform and prepare your child but avoid using words such as 'blind' as it can be more frightening for the child and it may not be entirely accurate. Very few people with Usher lose all their sight and do keep useful vision for a long time.
- Be honest and open but no-one knows the future. Parents often plan for the future and get bogged down with the 'ifs' and 'buts'. Children and young people find it hard to imagine themselves far into the future and they are more likely to think about themselves in that moment. If you don't know the answer, tell them that and find out together
- Clinical detail is less meaningful to young people than what happens with daily living
- Some young people may want information about the genetics of Usher – see <https://www.sense.org.uk/content/genetics-and-usher-syndrome>
<https://www.sense.org.uk/content/diagnosing-usher-genetic-testing-and-counselling>

What can be done to support a child or young person?

- Lighting and acoustics in the home and at school/college can make a big difference for many
- Support and educational advice about mobility and communication can help to build confidence. It is important to receive support from a specialist MSI teacher
- Inform your local authority so that they understand the future implications and can begin to support your family. Deafblind children and young people should have access to a Teacher of the Visually Impaired, Teacher of the Hearing Impaired and a Multi-Sensory Impairment Teacher.
- Apply for Disabled Living Allowance (under 16s) or Personal Independence Payments (over 16s)
- Access to assistive technology can help to make a difference. Hearing aid technology can help to compensate for vision deterioration
- Some young people can be affected by low feelings due to their Usher, especially as teenagers, so need a safe place to talk about their emotions and may need counselling support
- Having a rare condition can create feelings of isolation or social exclusion – networking, blogging and finding other young people with Usher can help
- Usher is thought of as a “hidden disability” – when people can't see it, it makes it difficult for them to understand or accept it. Raising awareness and developing understanding of Usher is crucial. Advise people about deafblindness and they will make adaptations to try to help you.
- Accepting the condition can be the hardest part. The support of family and friends is important.

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- Be positive, encourage your child to be ambitious.

What about the future?

- Don't limit what your child / young person does – let them try. If they have been riding a bike don't stop them now – what is different from yesterday to today just because they know they have Usher? Technology may allow activities and occupations which are not possible now but might be in the future. Support them to aspire and achieve a positive future
- Young people tell us positivity is key. Don't try to think too far ahead but deal day by day
- Young people with Usher can pursue a wide range of careers and hobbies
- Research and technology are advancing all the time
- A person with Usher can live a safe and happy life – they may just have to be more aware of their environment, make small changes or use some adaptations

What do children and young people with Usher worry about?

Children and young people are individual but some of the common worries we have experienced are:

- Protecting their family from being upset or worried about them
- Changes and not fitting in with existing peers
- Losing friends or not wanting to tell their friends – this is normal and they should be able to take control within their peer group
- If teens show moodiness or anger, and often make Usher the target, this is normal teenage behaviour but if they stop talking and withdraw, or if they becoming unusually emotional then seek help through your GP. Although not a recommendation, Sense holds details of counsellors/therapists with some experience of Usher.
- Having somebody to talk to – they need somewhere and someone safe to discuss any anxieties
- Communication with families and friends in the future – there may need to be some changes to enable communication
- The same concerns that all young people have around popularity, attraction to others, sports and ambitions
- Having a family of their own – it may help to understand the genetics or to meet other parents with Usher

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Where to go for further support?

- Sense Information and Advice line can offer guidance in finding the right support for you. Contact them on 0300 330 9256 or info@sense.org.uk
- Sense Children's Specialist Services can provide further advice and support to families and young people and connect you with other families living with Usher Email info@sense.org.uk
- Sense Usher Team can provide support to parents and young adults. Email usher@sense.org.uk
- Sense information on Usher at www.sense.org.uk/content/usher-syndrome
- Social services - www.gov.uk/government/topics/social-care
- Article talking about protecting the relationship between parents of children with special needs. <https://www.sense.org.uk/content/talking-sense-staying-together>

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