



**R N I B**

See differently

# Tough talks

Talking to children about  
vision impairment

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# Tough talks

## Talking to children about vision impairment

Parents and carers tell us that one of the most difficult and distressing parts of finding out that their child has a vision impairment is knowing how to talk about it with them.

This can be even more of a challenge if the eye condition is progressive and vision will get worse over time.

We have produced this guidance to support parents and carers as they think about this issue. We have spoken to parents of children with vision impairment and young people and adults with vision impairment themselves who have told us what they found most helpful.

## There is no right or wrong way

There is no rule book, or gold standard about how to address these difficult issues with a child or young person.

As a parent or carer, you are the expert in your own child. You know their personality, their strengths and weaknesses and the events and experiences that have made them who they are today. You know how they approach the world, how they handle change, things they love doing, things they find difficult, what motivates them and what brings them down. All of these factors are unique and will form the basis of how it might be best to talk to them about their eye condition.

## People who might discuss this

Consider who might be able to have this discussion with your child. This can be you alone, with other family or friends, or someone like a doctor, nurse, teacher or other professional, or a combination of all of these.

Most young people tell us that they have learnt about their eye condition from a parent, with additional information from eye health professionals.

## Getting help

Supporting your child yourself, and bringing in the experience of professionals who work with people with eye conditions and vision impairment, will probably give your child the best chance of feeling supported and informed about their own situation. You don't have to do it all yourself, though you will play a key role in helping your child come to terms with their condition.

Eye clinic staff will be experienced in talking to people at difficult times; use their support and expertise if you are unsure how to answer your child's questions. Your child's QTVI (Qualified Teacher of children with Vision Impairment) might also be well-placed to help you both.

## Plan ahead

While it can feel busy and rushed at a routine check-up appointment, some parents write to or speak to the Consultant beforehand so

they are prepared and ready to bring the subject up, or can offer an appointment at a time of day when the pace is more relaxed and everyone had chance to talk.

### **It might not be you, and that's OK**

Your child may prefer to talk about their eye condition with someone else:

**"I didn't want to talk to my parents. I wanted to ask my Teaching Assistant because I knew they wouldn't fluff around it and try to make it sound good."**  
(Natasha, 24 yrs.)

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### **Connecting with other families**

Some families find talking to other people in the same position helpful. They may have advice and tips on what worked for them or help you or your child hear from someone who has been through it and come out the other side. We can help you to connect to other families of children with vision impairment.

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### **Finding the right time**

There is no right or wrong time. You may choose to take some time to process the news of your child's diagnosis before you start talking to them about it. You may prefer to share the information straight away together.

The age of your child, their developmental level, your own response to the news and the



immediate impact of the diagnosis will all affect when it feels right to have conversations.

### **Changes right now?**

If your child's vision has changed, or will change suddenly, or if they require surgery or any supportive treatment such as medication, patches, glasses or contact lenses, you may want to start having some talks about what is happening.

If there is no immediate change to their everyday life, you may choose to wait until you have had a little more time to react to the diagnosis and find additional advice and support.

### **Allowing news to sink in**

Many parents first have the diagnosis confirmed at a hospital eye appointment. This can be the end of a long diagnostic journey or may be at the first appointment. Either way, both parents and children often do not take in all the information in one go, or do not think to ask questions about longer term visual outcomes.

## Growing up

For many parents, the child's eye condition was diagnosed when they were too young to understand, and it may be several years later that you feel the need to begin talking to your child about their eyes and their vision impairment.

It may be that your child has been discharged from routine appointments at the eye clinic if no further treatment or assessment is required. If you would like to enable your child to talk to an eye health professional in clinic about their condition, so that they can understand it for themselves, speak to your GP to arrange re-referral.

## Your child's right time is the right time

If your child starts a conversation themselves, or starts to ask questions, it is probably best to answer their questions and use the opportunity to talk. Your child may be more ready than you are to talk, and will sense if you are avoiding a topic, which may mean it becomes

scariest and more mysterious for them than the real thing.

Most young people find out about their eye condition through a combination of both a definite or structured conversation, where a parent or other adult has decided to talk about it, and then ongoing other conversations, usually started out of the young person's curiosity.

## "Now" and "Later"

You may want to think about "now" and "later" to frame discussions.

There might be some things to talk about **now** – for example experiences that are about to happen, such as an operation or some new glasses, or some new support in school.

Other things, such as facing further loss of vision in the future might be for **later** and you can explain to your child that you will keep having talks and that some things will be easier to understand when they are a bit older.

## What should we say?

Talking to your child about vision impairment is understandably very painful and difficult. It is natural to want to protect your child.

## Try to be as honest as you can

An open and honest relationship between you and your child will help you all as you all face the impact of vision impairment. It may be difficult in the future if you have to undo promises or inaccurate information.

## Be led by their questions

Simple "yes, I think so", "no I don't think so" and "I don't know" may be exactly what your child needs to clarify the issues that are on their mind. Don't feel you have to go into endless detail or go beyond the specifics of what they are asking about. If you haven't answered what they need to know, they will ask you another question.

# Facing the future

## Clarify assumptions

**“Will I go blind?” might be one of the hardest questions your child will ask.**

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It is important that you properly discuss this question, if your child asks it, so that you and your child both understand what you are talking about. Make sure you both mean the same things when you are talking about vision and blindness and understand each other’s assumptions.

Most people believe that blindness means that you can see nothing at all, so it is likely that this is the assumption your child is making when they ask this question.

It is very unusual for a child to be unable to see anything at all, to be completely “in the dark”. Most people who are registered blind, have some useful vision. Being able to tell the difference between

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light and dark is really important for sleep patterns and can be useful for locating where a window is in a room, for example.

Although your child might not be able to see well enough to read or recognise people, they may have enough vision to navigate around a room, to tell if there is an obstacle in the way. This level of vision offers a degree of independence.

## Getting informed

If your child has an eye condition which means that they will lose more vision over time, you can ask the Consultant Ophthalmologist how they might expect this to happen, over what time scale and what level of sight loss you might expect.

It is worth asking at each visit if the situation has changed: the consultant may not recall what they have already told you, or if the progress is what is expected or not.

## Coping with uncertainty

The consultant will be giving you this information about your child based on his or her current clinical tests, within a general understanding of the eye condition in all patients. Your own child will of course have their own unique experience and it is not possible to predict the future. Often there is considerable variation in the speed, severity and resulting levels of vision in individual patients who share the same eye condition.

For this reason, you probably can’t know, and therefore can’t tell your child exactly what to expect. You probably don’t know exactly what is going to happen, or when. It is therefore important, and perfectly acceptable, to say you don’t know exactly what will happen, if that is the case.

### Focus on the “can-do”

- **Talk about the things that are going to help.** You can reassure each other about asking for help from the hospital, specialist vision impairment education services (VI Services), habilitation and mobility services, charities and groups of other families of children with vision impairment. It will probably be comforting to your child to know that there are other people, besides their Mum and Dad, who are going to help.
- **Your child may have ideas themselves** about things to do or find out about that would make it easier to handle the news. If they have a chance to suggest what they feel would help, this is likely to be positive and empowering.



- **Talk about the activities your child likes doing, and how you are going to continue doing them.** You may like to try out audio-described films or TV, particular apps for people with vision impairment, books and magazines in other formats such as large print, braille or audio, or learning new skills like touch typing. You can find sport and leisure activities that are available to children and young people with vision impairment.

### **What shouldn't we say?**

#### **Try not to blame anyone**

It is not likely that your child's vision impairment is anyone's fault. (Though in some instances vision can be lost through accident or injury that may involve the fault of another person.) It is very common to feel angry and/or sad at the diagnosis of an eye condition, and we often seek explanation. Blaming others though, is unlikely to be helpful and may make it harder for a child to come to terms with their diagnosis.

#### **Avoid myths and false promises**

There are some myths about vision impairment that may be unhelpful. It is very helpful to be positive but try not to create expectations that may ultimately cause disappointment.

For example, blind people do not have extra special hearing powers, (though it is true that without sight, people with vision impairment can become very good at using the information from their other senses).



There may be exciting medical and technological advances which have big hopes for curing and helping eye conditions in the future. If you are investigating these, stick with trusted sources of information, like university or medical media, and check out any claims that seem more removed from the source of the information, such as the tabloid press.

#### **Consider your own feelings and their impact**

It can be a hard balance to find, and while you don't want to burden your child with your own feelings about their vision impairment you don't need to pretend that you aren't sad or worried too. It may be helpful to share these feelings together and talk about how you are all going to make it easier.

Your child may feel less isolated in their response if they know they aren't the only one having it. Some young people have told us they feel less able to discuss and ask about



their vision impairment because their parents found it distressing and upsetting.

You do need to stay a step ahead of your child in being “brave” or talking about things that are going to help – it is important that as a parent you are helping them more than they are helping you – but being alongside your child in their sad or worried feelings may mean that you can find some solutions together. You can also talk about the help and advice that you can get, as a parent, so that they know that they don’t have to be your support.

Remember that you are not the only adult in your child’s life who can help. Think about the other adults that they trust who can have a positive and supportive impact on your whole family.

### Talking to siblings and other members of the family

Brothers and sisters will want to know what is happening too. Make sure they aren’t left out of discussions and have a chance to ask their own questions.

As a whole family, you may like to talk about how you are going to answer other people’s questions. Siblings may well have to deal with more questions than the child who has the eye condition:

- “Why does your brother have a cane?”
- “Why do her eyes look funny?”
- “How come your sister gets a helper in school?”

Answering other people’s questions may be easier if you have short, practiced sentences that you are all comfortable with, but protect you from having to discuss painful topics or feel that your privacy is invaded. This can also be an opportunity to reinforce positive messages and suggest what would help.

- “She has \*name of condition\* which means her eyes work differently and she can’t see well in the dark.”
- “His eyes don’t see well, but if you say hello, he would love to talk about your Harry Potter book.”

If your child has an eye condition which is genetically inherited (can be passed between generations of a family), you can get advice from a genetic counsellor in order to understand the implications for your family as a whole and how to discuss these. If the hospital has not already referred you to a genetic counsellor, you can ask your GP.

# What if they don't want to talk about it?

That's OK! Forcing any conversation is likely to be unhelpful and will make everyone frustrated. You can be open and prepared to talk to your child about their eye condition at any point, but it is probably best to be led by them, when they are ready.

In the meantime, you can demonstrate support in other ways. As practical issues with home or school crop up, you can find solutions and put strategies in place to help. You can focus on their achievements, plans, hopes for the future and help them understand that vision impairment should not be a barrier to these. You can also comfort and keep them distracted if they are sad. Actions can be just as powerful as words.

## Encouraging acceptance and confidence

There can be different levels of a young person's acceptance of their vision impairment at any age. We know that some people still find it very difficult to acknowledge their eye condition, talk about it or discuss support as they are leaving school and entering adulthood. Young people who are struggling to accept their vision impairment might therefore be reluctant to disclose it, for example when applying for

a job or entering a new education establishment. This could prevent full access to the support, aids, adjustments or rights under equality law that could be helpful.

If this is the case as your child is getting older, talk to your QTVI, or another professional who is supporting your child, about how you might move forward together. It may be that counselling, peer support from other young people with vision impairment or older role models would help.



## Additional needs and conditions

Your child's eye condition may be part of a wider health issue that affects other parts of their body, and/or causes other disabilities.

If you and your child are facing increasing health needs or disabilities that are life-limiting, get support and help from professionals and parent networks that have expertise in helping families with difficult journeys.

**Contact.org.uk** has an extensive directory of family support groups for specific health conditions and syndromes.

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**www.togetherforshortlives.org.uk** has guidance about talking to your child about life-limiting conditions.

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## Getting further help and support

Ask to speak to our Sight Loss Counselling team by calling the RNIB Helpline **0303 123 9999**.

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Further information about emotional support, including a series of podcasts for parents and carers of children and young people with vision impairment, can be found at **rnib.in/EmotionalSupportCYPVI**

## References

Hewett, Douglas and Keil. (2015 (d)). **Support and information received by young people with vision impairments: technical report of findings October 2014 to February 2015**. University of Birmingham: Visual Impairment Centre for Teaching and Research (VICTAR).

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## **RNIB Helpline**

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