

About Deafblindness

1. What is deafblindness?

Deafblindness is a condition in which child has difficulty in seeing and hearing. The child usually has problem in communicating with you and taking care of his day to day needs. He also needs help in moving from place to place.

2. Are all deafblind children same?

No, all deafblind children are different. They have their own likes and dislikes. Their way of communicating with us is also different from others. The way we talk to them and assist them will also be different from other children

3. Are all deafblind children totally deaf and totally blind?

Very few deafblind children are totally deaf and totally blind. Most deafblind children have some amount of vision and/or hearing that they can use in their day to day life. It is important to know how much vision and hearing they have and encourage them to use it as much as possible.

4. My child is called 'multi handicapped'. Is this the same as being deafblind?

Being multi handicapped means the child has two or more disability conditions at the same time. If the condition is coming in the way of his learning and communicating with you, then s/he will benefit from a deafblind programme

5. Are there other children like my deafblind child in India?

Yes, there are many other deafblind children in India. They can be seen in cities and villages of India. At present, we have already come across 2000 deafblind children through out India. However experts say there might be around 500,000 deafblind people in India.

6. My child is blind and does not speak. Is he also deafblind?

Your child may be having other difficulties such as learning disabilities or speech problems. He is therefore unable to speak. He may benefit to understand you better and speak with you after getting training in the same way as deafblind children. Do contact a deafblind programme. Your child is however not deafblind. He is visually impaired having additional speech difficulties.

7. Do children sometimes acquire this disability later in life?

Children with good sight and hearing, sometimes develop this condition. There could be many reasons, such as, brain fever, epilepsy and accidents. Most importantly, at times there are genetic reasons in a family because of which a child can acquire deafblindness at a later stage.

8. What causes deafblindness?

Premature birth, Rubella or German Measles in pregnant mothers, lack of proper medical care at the time of birth and Usher's syndromes are some of the major reasons for deafblindness in our country.

9. What could be the reason for my child being deafblind?

Your doctor would be the best person to tell you the exact reason. However depending on your medical history, the child's health and similar cases in your near and distant family members, you

will be able to know the real reason for your child being deafblind. One thing is for sure – it is not because of any mistakes or sins on your part!

10. Will my other children also become deafblind?

This will depend on the diagnosis of the cause in your deafblind child. If it is due to a genetic (Family History) reason, then you will need to go through further tests and advice before having your next child. Contact your family doctor for further advice.

11. What precaution must I take during pregnancy to avoid having a deafblind child?

Please do rule out any genetic (family history) condition that may lead to deafblindness in children even before you decide to have a child. Be in touch with a doctor for regular advice for a healthy pregnancy. Make sure that you have been vaccinated against Rubella before you plan a baby.

12. My child looks different from other deafblind children. Why?

Some deafblind children have facial features that make them look different from other deafblind children too. One such condition is known as CHARGE. Children with CHARGE association have the following features:

C: Coloboma of the eye which means that there may be white spots visible on the child's pupils.

H: Heart disorders such as mal formed heart or whole in the heart

A: Artresia indicating that the nasal and ear openings are not completely formed

R: Retarded Growth, children looking much smaller than their age

G: Genital Hypoplasia or incomplete development of private parts in the child

E: Ear Anomalies: Ears are not completely formed or look very different from our ears

Besides this Hydrocephaly leading to deafblindness means that you child has a head size that is larger than children of his age. And Micro cephalic head means a head size that is smaller than children of his age. Down syndrome children also look different from others.

13. Who can tell me how much my child sees?

The ophthalmologist will be the right person to tell you the nature and extent of your child's vision. Please remember that the specialist may be seeing a deafblind child for the first time. The information that you give him will help him to make the best diagnosis for your child. Do remember to ask him, how the remaining vision is going to change in future. And what are the best ways to help your child see better.

14. Who can tell me how much my child hears?

Please contact an audiologist, he will be the best person to tell you, how much your child hears. But please try and remember, the audiologist may be seeing a deafblind child for the first time. The information that you can give him will be the most helpful for him to make a diagnosis. Hearing is not something that a specialist will be able to determine right away in one appointment. You may need to work along with the audiologists for a longer period of time to get the true picture.

15. Why does my child have difficulty understanding me?

95% of what we learn about the world comes from what we see and hear around us. When both these senses are affected, it makes the deafblind child very vulnerable to learn things around him and understand you. This does not always mean that the child is mentally retarded also.

16. Will my child ever learn to read and write?

Deafblind children can certainly learn to read and write. And many in the country are doing so. But they have special ways to learn to read and write. Please ensure that he is getting opportunity to use these special ways. Sometime, due to many other difficulties such as mental retardation, major challenges in communication etc, children are not able to learn to read and write, but they can still learn to take care of their needs in the environment around them to their best possible abilities

17. Why are they not teaching my child to write in Braille?

Not all blind children need to learn by Braille, same with your deafblind child too. He may be having enough residual vision that he can use to see things and learn. He may also have additional problems that will make it difficult for him to understand, remember and reproduce Braille. Forcing Braille on him will make it a frustrating experience for him. Talk to your child's educator about the best method for him to learn to read and write.

18. Will my child not learn best in the hostel?

No, your child will not learn the best in the hostel. There are many reasons for this. Most importantly, just like your other children, he needs you in his childhood days more than any body else. Deafblind children take a long time to learn to take care of their day to day needs and function in their immediate world. Staying in the hostel may teach him to do all these – but in the hostel / school environment only. Once he comes back home, most of his learning in the hostel will be of no use to him as he will have to relearn everything. Being away in the hostel will not help you to learn to communicate with him in his way. Even when he comes back home, he may not find it easy to talk to you and you may not be able to understand his needs. This will lead to more difficulties in your relationships.

19. Why do I need to consult a neurologist so frequently?

If your child has epilepsy, it is important to stay in touch with the Neurologist on a regular basis. The pattern of epilepsy changes very often although you may not be able to see it. And your child may require different types or doses of medicines.

20. There are no deafblind schools where I live. Where can I ask for help?

Do not despair! Please approach the blind school, deaf school or school for mentally retarded children. They may have someone trained in multiple disabilities that can help you and your child. If you still do not get any help, contact us or the nearest centre from the list given at the end of the book till a school comes up for your child where you live. You may also identify a family member who is interested to get trained to work with the child. We can provide you that support.

21. How can other members of my family help?

Your deafblind child needs his brothers and sisters, grand parents' uncles and aunts to love him and give him time. They can talk to him; play with him, help him to walk or see better. They may also help him to learn to read/write and colour pictures. They can take him to the market, sing and dance with him. Your child will enjoy doing all those things that other children do at his age. But he may need a little bit more time or help to do it. And that is what other family members may be able to give him

22. Are other deafblind children learning to take care of themselves?

Hundreds of deafblind children in the country are now receiving education and training. They are getting this training at homes and schools. Such training is helping them to take care of their day

to day work such as toileting, eating, sleeping and playing, communicating and moving from one place to another. Many deafblind children are also going to regular schools – learning to read and write and use the computers!

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