National Deaf Children's Society

For families

My baby has hearing loss

We believe nothing should hold deaf children back.

Contents

We use the term ‘parent’ to refer to all parents and carers of children.

Acknowledgements

Our thanks to the members of the National Deaf Children’s Society Parent Panel Facebook group for their kind words and thoughtful contributions to this resource.

1 Introduction

Learning that your child has hearing loss may come as a shock. You might have lots of questions or feel different emotions. That's OK. Acknowledge the way you feel and be kind to yourself. The National Deaf Children's Society is here to support you and your family every step of the way.

This resource covers some of the main questions commonly asked by parents who've just found out that their child might have hearing loss. We asked education and healthcare experts to answer each question. We also asked families with deaf children what advice they'd give to a parent just like you. Each of the parents and grandparents who contributed to this resource has stood in your shoes. In this resource, they'll share some of the things they've learned along the way.

Having hearing loss is only one part of your child's identity. Don't forget to enjoy all the other wonderful things that make your child the special person that they are.

We use the term 'deaf' to refer to children with any level or type of hearing loss, from mild to profound. This includes deafness in one ear and temporary hearing loss such as glue ear.

The language you and your family use to describe your child's deafness is a personal choice. You may prefer to use terms like 'hearing loss' or 'hard of hearing.' Your local health and education services may use other terms. As your child gets older, encourage them to describe their deafness in the language that's right for them.

Every deaf child is different, and every family is too. This resource includes messages from parents living all over the UK. Their children:

- have different levels and types of deafness
- use different hearing technology
- use different communication approaches
- have different experiences of professional support

Some children were identified as having hearing loss during the newborn hearing screening test. Other children may have been identified months or even years later.

The decisions made by the parents who contributed to this resource won't always be relevant to your child and your family. You might agree with some comments and disagree with others. We hope that the experiences and advice included in this resource can help you to make the right choices for your child and your family.

2 Causes of deafness

There are lots of reasons why a child might have hearing loss. It's very unlikely that you could have done anything differently to change your child's hearing.

Around half of deaf children are born with hearing loss. Most children who are born deaf have a genetic variation which affects their hearing. Genetic deafness can be inherited (passed down through families). However, most children with genetic deafness have no family history of hearing loss.

Hearing loss at birth can also be caused by an infection during pregnancy, such as congenital cytomegalovirus (cCMV).

Around half of deaf children become deaf after birth. This is especially common in premature babies who may:

- develop an infection which causes deafness
- be treated with ototoxic medication (medicine which causes deafness as a side-effect)
- experience severe jaundice or a lack of oxygen during birth

Your audiologist can give you more information about tests to find out the cause of your child's hearing loss. However, the tests will only be able to identify the cause of deafness in around 40 to 50% of children. It may not be possible to find out exactly what's caused your child's hearing loss.

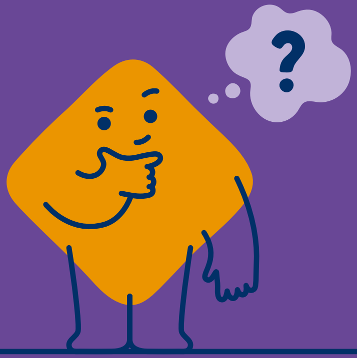
In time, most families come to feel that what caused their child's deafness is less important than how they support their child.

Some parents have asked…

“Did I do something wrong during pregnancy?”

“Is it my fault?”

“What caused my child’s deafness?”



Other parents have said…

> Don’t blame yourself. I did, I felt guilty for a long time. But over time I learned that it’s not our fault. Deafness can just happen, it does just happen and there’s absolutely nothing we did in pregnancy to cause it. Don’t be hard on yourself.

> Don’t allow yourself to fall down the rabbit hole of constantly blaming yourself. All mums do this at some point. It’s not worth the guilt and upset. Most humans carry a defective gene of some sort, and many go through life without knowing about it. For the small number who end up with children born with a hearing loss or a disability due to those genes, it happened at conception. Nothing you could have done in pregnancy would have prevented it. It was already done. It is what it is.

> I researched possible causes of deafness over and over again. I realised, for me, it’s just part of who my son is, in the same way as his eye or hair colour.

> When you first find out, you're trying to make sense of everything and sort through enormous amounts of information. Your child's deafness is not your fault. You're doing your best to help your child.

> I cried over this for months. It took time to realise that the cause doesn't matter. If I spent all my time feeling guilty, I would miss out on how perfect and amazing my son is.

> It's natural to want to try and find meaning in something you haven't experienced before. It's also easy to want to blame yourself for the 'what ifs,' in case the situation could have been avoided. However, some things are outside of our control or understanding. It can be more helpful to concentrate on what you can control in your situation now.

> We still don't know the cause, but we have learned to live with that and adapt, guided by our daughter who is flourishing!

> My daughter's deafness is caused by congenital cytomegalovirus (cCMV). When I learned about cCMV, I couldn't help but think I'd done all the things they say can spread it, like sharing food and drink with my toddler during pregnancy. But a year or two after, I began to blame the healthcare system for not informing me about ways to avoid CMV infection during pregnancy, and for not training more doctors, nurses and midwives about how to spot the signs of cCMV.

> I felt like it was my fault. I think, until you find out the cause, you'll always wonder, even though it's highly unlikely and largely a stress reaction to news you weren't expecting. We agreed to the genetic testing and found it was a combination of our recessive genes. You can't predict that or change it; it's a game of chance.

> I didn't like being told I shouldn't feel like I did, or blaming myself was stupid or wrong or to not do it. I also didn't like toxic positivity, and I didn't like my feelings being invalidated. I needed acknowledgement that that was my experience, and then guidance towards the bigger picture.

3

Levels and types of deafness

If your baby has been referred for further testing after their newborn hearing screening, this does not necessarily mean they have hearing loss. For example, fluid in the ear canal following birth can affect the results of newborn hearing screening.

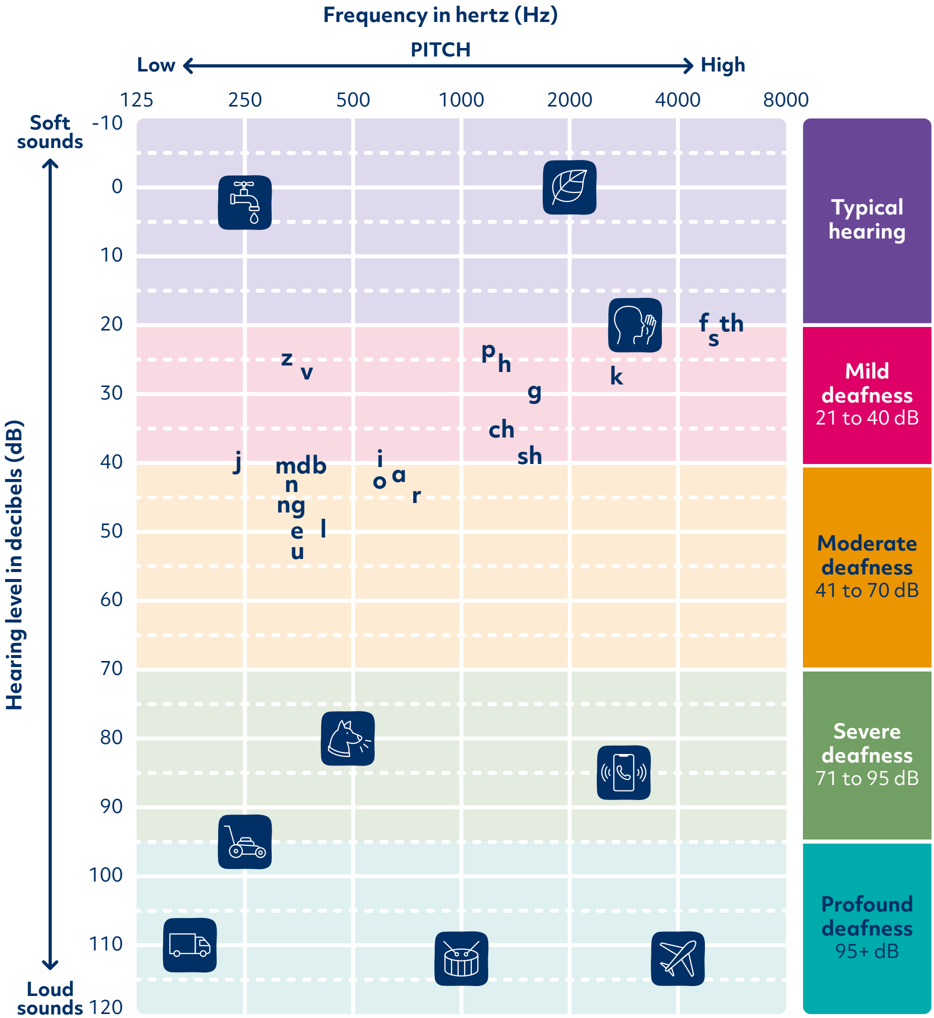
Your child’s hearing tests will be done in an audiology clinic. The tests might take a long time. You may need to attend several appointments to get an accurate picture of your child’s hearing. Your audiologist should always explain the tests they carry out and how long your appointment might take.

If these tests confirm your child has hearing loss, the audiologist will explain the level and type of their deafness and what this means.

There are different levels of hearing loss, described as mild, moderate, severe, and profound.

Hearing loss can affect one ear (unilateral deafness) or both ears (bilateral deafness).

It’s very rare for a child to be born with no hearing at all. Most deaf children have some level of hearing, known as ‘residual hearing.’



Your audiologist will talk you through the results of your child's hearing tests and discuss the sounds your child can and cannot hear. What happens next will depend on your child's level and type of hearing loss.

If you're not sure about any of the information you've been given, you can go back and ask the audiologist to explain. Take a list of questions with you to your audiology appointments and make sure you fully understand the answers they give. Ask for copies of test results and reports for your records. You could even ask to record the audio of your child's appointment on your phone, so you can listen back later.

You need to feel comfortable with the management of your child's hearing loss. If you're not happy, it's OK to ask for a second opinion. There's no legal right to have a second opinion on the NHS, but requests for second opinions are rarely refused.

As your child gets older, their hearing may change, or it may stay the same. If you think your child's hearing has changed, contact your audiologist and ask for another appointment.

For more information about hearing tests and the different types and levels of hearing loss, order our resource, 'Understanding your child's hearing tests.'

ndcs-bookshop.myshopify.com

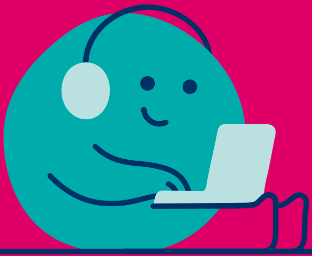
Some parents have asked…

“Will their hearing get worse over time?”

“How much can they hear?”

“What does the world sound like to my baby?”

“Are they sure about the diagnosis?”



Other parents have said…

> Your child's hearing might stay stable and not change for years. In other cases, it can deteriorate. The best advice I can give is to try not to worry about it. What will be will be. There's so much support and help available now to help manage changes in hearing.

> Get to know your child and any signs that could indicate a change in deafness. For us, our child's behaviour becoming difficult was always an accurate indication of hearing deterioration, so whenever this happened it was straight to audiology! Try not to fixate as you can never predict whether it will or won't happen, but be prepared that it's a possibility.

> My child has mild hearing loss, but I was still upset and shocked that this is how life would be navigated. Something about a diagnosis of hearing loss just felt like it didn't matter in this moment, but what did it mean for the future?

> My son's hearing has got worse, but that just means he needs a little bit more support.

> Try not to fixate on your child's level of deafness. Embrace your child for who they are. With help and support from the National Deaf Children's Society and local support groups like deaf clubs and pre-school groups, you'll be fine.

> Your child's hearing might not actually change, but their hearing test results can change as they get older as they're better at engaging with audiology appointments.

> We identified our daughter's hearing was deteriorating and had to fight to be heard. Be aware that this can happen and keep a close eye on things so that your child's hearing aids are programmed correctly for their level of hearing loss. My daughter is now 13. She has no natural hearing left at all and does fab with her cochlear implants. She is thriving.

4

Language and communication

Communication begins in the womb, through touch, voice and movement during pregnancy. After birth, responding to your touch, making noises and copying your expressions are all early signs that your baby is communicating with you.

As your baby grows older, they'll begin to develop language. Some deaf children use spoken language, and some use sign language. Many use a combination of both or choose to speak in some environments and sign in others. Every deaf child is different, and what works for one family may not work for another.

Making choices about communication can feel overwhelming. Remember, the choices you make now do not have to be permanent. The way your child communicates will evolve as they grow.

If you're concerned about your child's speech and language development, talk to your Teacher of the Deaf (ToD), GP, health visitor or nursery staff to ask for a referral to a speech and language therapist.

Speech and language therapists work as part of a team with your child's audiologist and ToD. They help your child and those around them to communicate as effectively as possible, in sign language or speech.

Learn more about communicating with deaf babies and toddlers, including activities to enjoy with your little one, on our website. Visit **ndcs.org.uk/communicating-with-baby**.

Some parents have asked…

“What does this mean for speech and language?”

Other parents have said…

> My little man has bilateral cochlear implants. He signs at full volume and talks all the time, something I wasn’t sure would be possible. His words aren’t always as clear as other children, but he is doing amazingly. I got just as excited the first time my son signed ‘mum’ to me as I did when he said his first word.

Learning sign language

Sign languages are visual languages that use hand shapes, facial expression, gestures and body language. Like spoken languages, sign languages have their own vocabulary and grammar.

The main sign languages of the UK are British Sign Language (BSL) and Irish Sign Language (ISL). Like any spoken language such as French or Spanish, it takes time and practise to learn and use BSL or ISL fluently.

As well as being a method of communication, sign language is also an important part of a shared deaf cultural identity.

There are lots of reasons why families decide to learn sign language. Some families learn to sign because it will be their child's first language. Other families raise their children using both sign language and speech, so that their child can choose how they want to communicate in the future. Some families choose to learn a few everyday signs with their child or go to sing and sign classes.

Some people worry that using sign language will mean their child does not learn to speak. In fact, learning sign language can help you to communicate with your child at an early age. As long as your child is exposed to good quality spoken language as well as sign language, there's no evidence that learning to sign will stop them developing speech.

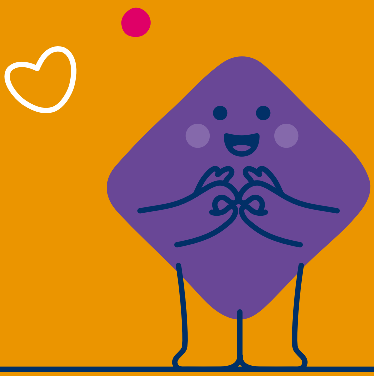
Find out more about sign language at **ndcs.org.uk/sign-language**. You could also speak to your Teacher of the Deaf about support for families learning to sign in your local area.

Some parents have asked...

“Do we need to learn to sign?”

“Where can I learn sign language?”

“What kind of sign language should we learn?”



Other parents have said…

> There's no harm in learning sign language. It activates the same part of the brain as spoken language. Many cochlear implant teams advise not learning BSL when implanted but I feel this is not the best advice. Sign language is a beautiful language that can help children feel included in all situations and can help with total communication.

> I'd say take time to process the news first. Don't do anything you aren't comfortable with. We learnt a little sign to make the early stages better for us all (basic signs like milk, more, cuddles), but also to encourage our son to accept his disability and to be part of the Deaf community.

> Do whatever it takes to communicate with your child and ignore the 'no signing' advice. My son is now 21 and signed when he was younger before having cochlear implants just before he was 3. He's just gained a degree in neuroscience from Manchester University. It didn't hold him back!

> My first question to audiology was, ‘Should we learn sign language?’ Sadly, they told us to try hearing aids first. Given they are the professionals, I took their advice. Eight months later, our Teacher of the Deaf told me that ‘perhaps as a family we should start learning BSL’. That’s 8 months without language! My daughter is now 6 and is a fluent BSL user. But I’m still outraged by what I was initially told.

> While your child may be able to use hearing aids or have cochlear implants, sign language is still a great way to communicate, especially in the early days. I wish we’d had access to learn BSL rather than Makaton in the early days, as BSL can be used throughout your life.

> I did Level 1 BSL in my daughter’s second year of life. It was a lot of time, effort and money, and my daughter learnt to speak quicker than I learned the signing! We don’t really use it much and so it was quite an overhead when I was exhausted with a young child who had lots of appointments. However, I wanted to ensure she wouldn’t be left without language if she didn’t learn to listen and speak. Learning BSL was an insurance policy in a sense, which put my mind at rest.

> Sign supports early language development and is a great way to communicate, especially in noisy environments. You might want to start by seeing if there are any baby sign classes near you.

> There's no harm in using sign and spoken English with your deaf child. Even if they do learn speech, sign is only going to help aid their development. It also helps them to be less frustrated because they have another way to communicate when they don't have words yet. My son has cochlear implants and is responding to sounds, but when he takes his processors off, he's completely deaf. I don't want the conversation to end there. For me, it's important we use sign as a family so that my son is included, whether he's wearing his processors or not.

> My son was diagnosed with progressive hearing loss when he was 3. He's now 5 years old and is profoundly deaf. We've just started to learn BSL, but I wish someone had advised us to learn earlier. Healthcare professionals told us to use Makaton, and it did help him to communicate more and develop some words, but if I could go back in time, I'd definitely do BSL from thebeginning.

> Start to learn BSL as soon as you can. Babies and toddlers pick up the signs very quickly. As a grandparent of a deaf child, I felt that I was being proactive as I learnt and used the signs. It definitely helped to reassure me.

> You may be told you won't need to learn to sign, or that you should use speech, but BSL could end up being a huge part of your life.

> Sign helps with spoken language. My husband and I are both deaf and BSL is our first language. Our deaf daughter was taught BSL from birth and it really helped to lessen the frustration that comes with toddlers who don't yet have full spoken language. My two hearing sons' first language was BSL too and being able to communicate with them before they could speak helped so much. Technology fails and breaks, so it's useful to have another source of communication while you wait for technology to be fixed. Also, even with hearing aids and cochlear implants, deaf children don't always pick up everything that's being said. Sign language helps to bridge the gap.

Learning to speak

In the UK, most deaf children have a spoken language as their first language.

Speech is made up of many different sounds that form words. These sounds vary in pitch (frequency) and loudness. The audiogram on page 12 shows where common speech sounds and everyday noises typically occur.

Children develop speech through hundreds of hours of interaction with adults. To learn how to hear and process speech, deaf children need to be able to hear speech through their residual hearing, hearing aids, or implants.

Your child's audiologist or Teacher of the Deaf (ToD) can help you understand which speech sounds your child can hear with and without hearing technology.

There are lots of ways you can help your child learn to listen and enjoy listening to you. For example, you can help your child tune into your voice by:

- singing
- changing the loudness or pitch of your voice
- using different voices when telling a story
- using visual cues and objects to show your child what you're talking about

Adding visual information to your speech, such as pointing, gesturing and facial expression, can help your child to make sense of what you're saying.

Deaf children may take longer to process speech. Try to be patient, giving your child plenty of time to process what's been said and respond.

Studies show that once a child begins to understand speech, they quickly develop their own spoken vocabulary.

A late identification of deafness does not mean that your child cannot develop either spoken or signed language, but their language skills may be delayed. If you have a ToD or speech and language therapist, they can support you to create the best possible language environment for your child.

With the right support, lots of deaf children can learn more than one spoken language at the same time. For example, a deaf child might grow up using Urdu at home and English at school. Most bilingual children have a preferred language, which is usually the language that you and your family use at home in everyday conversation. Some children naturally use different languages with different family members. There's no right or wrong first language for your child.

Many deaf children also enjoy learning modern foreign languages at school, such as French or Spanish. Schools should make adaptations to support this.

If you're concerned about your child's speech and language development, talk to your ToD, GP, health visitor or nursery staff to ask for a referral to a speech and language therapist.

Find out more about supporting your child to develop spoken language.

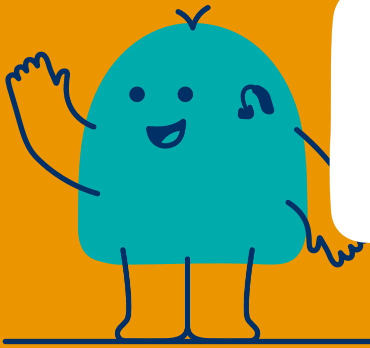
ndcs.org.uk/spoken-language

Some parents have asked…

"Will they be able to speak?"

"Can they hear my voice?"

"My family is bilingual. If my child develops verbal language, can she learn two spoken languages, or do we stick to English and sign?"



"Will he be able to speak as he was diagnosed late?"

Other parents have said…

> My son is 8 and has bilateral cochlear implants. He talks, sings and has a fantastic range of vocabulary. He is clear and, other than his obvious ear gear, you wouldn't know from listening to him that he's deaf. It's all possible.

> He's learning English and BSL and will come home having learnt snippets of foreign languages. He hears me and whispers secrets to me. He will however remove his 'ears' to ignore me asking him to do his reading or to tidy his room!

> My daughter has done 2 years of French and German at secondary school and excelled at both. She's chosen to start learning Spanish next year. She streams Duolingo daily from her phone into her cochlear implants. Her teachers use her radio aid in lessons, and she will get a live speaker for language exams.

> My little boy is now 5 and profoundly deaf in both ears. He can say a range or words; they aren't all clear, but people who know him can tell what he's saying.

> This was my first question. My son has excellent speech, can use and understand BSL, and never shuts up. Nothing stops him doing anything!

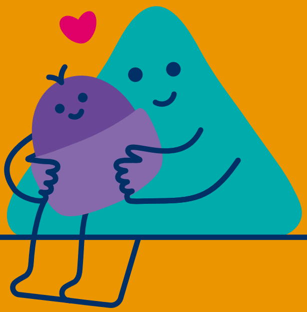
> We use a radio aid at home and at school and he can hear our voices. In a quiet room, he can hear us without the radio aid and just hearing aids.

Bonding with your baby

When it comes to bonding, everyday touch, smiles and play are just as important as being able to hear your voice. You can interact with your baby in lots of different ways. Seeing your face and feeling you close tells your baby that they are safe and loved.

Some parents have asked...

> **“How will I bond with my baby if they can’t hear my voice?”**



Other parents have said…

> My bond is as strong with my profoundly deaf son as my hearing son. We still enjoyed lots of snuggles, singing and playing.

> The 'advice' my doctor gave me was, 'Just treat her like a normal baby.' There were so many things wrong with that. I remember thinking, 'my baby is normal,' and as a first-time mum, I didn't have much to compare to. But connecting with my baby didn't need voice; we spoke with our hands and pictures. She still laughed, she still cried, and she still chucked food she didn't like on the floor or up the walls. This was our normal.

> It's wonderful to bond with your deaf baby through warm smiles and physical touch, showing love and empathy. Singing can be a great way to connect, as deaf babies can feel the vibrations.

> It's different for everyone. We were lucky as we had support from our Teacher of the Deaf and health visitor. If you're struggling, open up to your health visitor or GP.

> My son is hearing and was a happy self-soother, despite me wanting all the snuggles. My daughter was born with hearing loss and loved cuddles and nap trapping us! She absolutely adores her big brother and bonded amazingly with him as well!

> Your baby is still your baby, whether they're deaf or not. They still need you to be their everything.

> Get to know your child. Enjoy your child and show them how incredible they are and what they can do.

5 Hearing devices

Many deaf children and young people use hearing devices such as hearing aids, bone conduction hearing devices, or cochlear implants. Your child's audiologist will talk to you about which hearing devices could be suitable for your child, considering their age and their level and type of deafness.

Hearing aids are the most common form of hearing device. They work by making sounds louder and clearer. They're customised for each child's type and level of deafness.

Cochlear implants are surgically implanted devices that give a sensation of hearing by using electrical signals to stimulate the auditory nerve. In the UK, cochlear implants are only offered to deaf children with severe to profound hearing loss in both ears, who get little or no benefit from hearing aids.

It's common for babies and toddlers to try to take their hearing aids or implants off. We have advice about keeping hearing devices on little ears on our website.

Deciding whether to use hearing devices is a personal choice. Most deaf children get on well with their hearing devices and can hear sound close to typical hearing levels. However, the sound they hear will be different to sound which is heard naturally. Even with the best hearing devices, there will be times when your child has difficulty hearing compared to hearing children. They may benefit from trying different types of assistive listening technology. Your audiologist can tell you more about this.

As your child grows up, they will decide for themselves whether they want to use their hearing devices.

Find out more about the full range of hearing devices available at **ndcs.org.uk/hearing-aids-and-implants**.

Some parents have asked…

“How can hearing technology help my child?”

“Could hearing aids help?”

“What are cochlear implants and are they suitable for us?”

“What will his future look like with cochlear implants?”

“Will she wear hearing aids forever?”

Other parents have said…

> There is so much technology that helps with deafness, we were honestly amazed. Our girls will thrive!

> Our daughter was identified with mild hearing loss when she was 4 and recently got her first hearing aids. She's just started school and is loving life. We've tried to make the whole experience as positive as possible for her and she proudly talks to her new school friends about her hearing aids. Her confidence has come on leaps and bounds since getting her aids. It's been fascinating over the summer when she's asked about sounds that are new to her that we've always taken for granted, like birds, grasshoppers, hedge trimmers and motorbikes.

> Our son has been implanted for nearly 3 years and it was the start of an exciting journey. He went from showing no reaction to sound to singing full volume his favourite songs, of which there are many!

> Giving our son bilateral cochlear implants has been truly life changing. Before, he had no access to sound and lived in a completely silent world. As hearing parents from a hearing family, we didn't know any sign language at the time, which made communication even more challenging. Once he received his implants, it was like a door opened to an entirely new world, suddenly filled with sound, from chatter to playful crashes and bangs! With access to hearing, he became a different child – more engaged, more alert, and noticeably happier. Having both cochlear implants and sign language has been an incredible combination. It gives him the flexibility to choose how he communicates. Some days he prefers a quiet world with sign, other days he wants the full experience of sound. He now has the best of both worlds, and it was the best decision we could have made for him.

> As the area I live in has no deaf schools or schools with deaf bases, I knew my child needed the best technology available. I was born profoundly deaf and had hearing aids which did nothing and school was a struggle. I couldn't hear anything and wasn't allowed to learn sign language, so it was very isolating growing up. When my daughter was born profoundly deaf, I immediately asked for cochlear implants to be considered for her. Best decision ever. She has had her struggles with the implants, but she loves to hear, listen to music, and have conversations with her close friends in school.

> We come from a hearing family with no history of hearing loss. Our daughter was born with unilateral severe to profound hearing loss which eventually deteriorated into bilateral profound loss just before she turned 3. Our daughter received her implants just over a year ago and it's been the best decision for her (I hope she feels the same when she's older). She has always wanted to communicate with others, showing anger and frustration when she's been unable to get her point across, whether that be in sign language or using facial expressions. Now she has access to sound her speech is coming along incredibly fast and she's a much happier child. I feel like all the doors are open for her future now!

> Cochlear implants are our daughter's miracle! The gift of sound to play her clarinet in orchestra and sing with school choirs, to swim in time to the music underwater with her synchronised swimming team and to chat to her friends. Between her cochlear implants and radio aid she accesses an amazing education too. We love her 'ears'!

> My son has hearing aids, but it will always be his choice whether or not he wants to wear them.

What if hearing devices don't work for my child?

There are many reasons why deaf children and young people may not use hearing devices. Some cannot use hearing devices or do not benefit much from them because of their type or cause of deafness. Others choose not to use technology.

Your child's audiologist can tell you about which hearing technology would be appropriate for your child and support you during any assessments for implants.

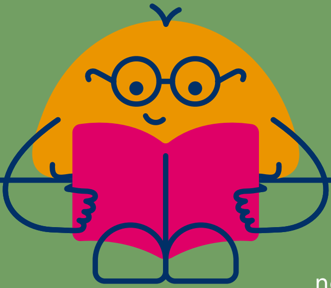
If hearing devices would not benefit your child, or if you choose not to use them, your Teacher of the Deaf can help you explore other ways to support your child.

Some parents have asked...

“What if hearing technology doesn’t help my child?”

“What if it damages my baby to have this technology?”

“Will hearing aids work?”



Other parents have said...

> We'd always thought that our daughter 'might' benefit from the use of aids/implants/the unknown! However, she was unsuitable for everything. She has a profound bilateral loss, with no hearing at all. Learning BSL from the get-go has been crucial for us.

> My daughter was born profoundly deaf. I knew cochlear implants were an option, but when I began to research the process, I was put off by the thought of surgery when my daughter was a healthy, happy baby. My daughter wore hearing aids until she was 3. One day she took them out and refused to put them on again. She's made her communication preferences clear and has flourished using BSL.

> Learning BSL opened a new world to me, and I fell in love with the Deaf community and culture. I stopped thinking about deafness as a disability as I met so many positive Deaf role models. My daughter is happy being Deaf, has no interest in the world of sound and can express herself beautifully in sign.

> If my daughter decides she wants a cochlear implant in the future, I would 100% support her decision. I feel that she deserves autonomy in making that choice.

> My advice to another family would be, ‘don’t be afraid to say no’. I feel that many parents are rushed into making the decision before they’re fully informed and before the child can express their own preference. To me, my daughter is perfect exactly the way she is, and her Deaf identity is something to be proud of and celebrated. I like the perspective that people are disabled by barriers in society, not by their impairment.

> I wish parents would put the same effort into learning BSL as they do in trying to make their Deaf child hear.

6

Getting the right support

The first few weeks and months after your baby is identified as deaf can be an uncertain time. You may feel worried about how you can support your child while waiting for support from professionals. Enjoy getting to know your new baby. Spend time as a family cuddling and playing, and try to settle them into a comfortable routine.

Babies are learning about their world every day, whether they're hearing or not. Talk or sing to your baby about what you're doing and what's happening around them, even if you're not sure what they can hear. Make sure your baby can see your face, copy the noises and facial expressions they make, and play games together like 'peek-a-boo'. Don't forget that cuddling, comforting, rocking, smiling and singing are all forms of communication.

There will be lots of decisions to make in the future, and you may feel overwhelmed by the choices you're being asked to make right now, but most of them can wait. Just take things one step at a time. The decisions you make now don't have to be permanent. What's right for you and your family now may no longer be right in a few years.

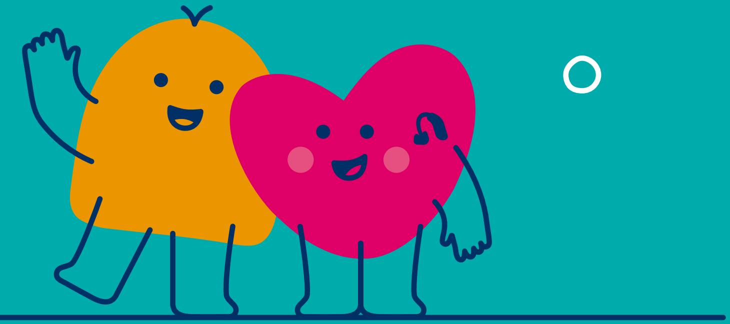
Find out more about communicating with your deaf baby or toddler, including activities to enjoy together, at **ndcs.org.uk/communicating-your-deaf-baby-or-toddler**.

Some parents have asked…

“What do we need to do to help him?”

“What can we do?”

“How can I support my child?”



Other parents have said...

> Get into the habit of having subtitles on the TV, even when your child is young. I've got so used to subtitles I now can't watch TV without them, but my son has dramatically increased his reading capabilities with them being on too!

> Don't dwell on the negatives. Our children need us to pick ourselves up and crack on. I always recommend reading the poem 'Welcome to Holland', by Emily Perl Kingsley. It's still on my wall now and it's so true.

> We use a radio aid at home and at school to help him hear our voices.

> My advice is to learn sign language, regardless of your child's level of hearing loss. We listened to our healthcare provider who told us our daughter would adapt with one-sided hearing loss, and then suddenly her other ear deteriorated and she was left language-deprived while we rushed to get help from speech and language and a Teacher of the Deaf.

> Surround yourself with positivity and contact your local deaf club. Once you've come to terms with your new, different but wonderful path supporting your bundle of joy, decide what you're happy with. Acceptance and knowledge are power.

> Adapt your home to support an easier listening environment. Carpets are better for sound than wooden flooring which can echo. Reduce background noise where possible such as a TV on in the background. If your child has cochlear implants, consider anti-static sprays on trampolines and plastic slides in the garden. Spend time reading – it's the best way to soak up language. You can sit in front of the mirror with your child on your lap so they can see your lips or signs, or sit opposite them at their level.

> Listen to your gut and trust your parenting skills! Have high expectations and don't let deafness stop them doing anything! Give yourself time to grieve but educate yourself and do your research. Parenting Facebook groups are an amazing resource. The early years are so important – make the right things happen. Decide how to spend your limited time, energy, money and resources. For example, we chose not to fight for an education, health and care plan (EHCP). We used our time and energy on other support for our daughter. Everyone's circumstances will be different.

Getting support in your local area

The support you get from professionals will vary depending on where you live and your child's age and level of deafness. You may be referred to professionals who work in healthcare, education, and social services. This could include audiologists, ear, nose and throat (ENT) consultants, speech and language therapists, teaching assistants, and social workers.

Many families with a deaf child will be supported by a Teacher of the Deaf (ToD). Your ToD is likely to be the main person responsible for coordinating early years support for your family. They may visit you to support with new hearing technology, communication choices, and planning for the future. Once your child starts school, they can help them to settle in and make sure the school is meeting their needs.

For deaf children of school age, ToDs provide a link between a deaf child and their school. They help schools to understand what they can do to make teaching and learning accessible and how to use and look after hearing technology. They also carry out specialist assessments.

Whether you have access to a ToD, and how often they visit, will depend on your child's needs. If you feel you and child could benefit from a ToD, contact your local sensory support service to find out what could be available.

Local deaf children's societies and support groups are a great way to meet other families of deaf children and find out about other support available in your area. They may run social events and activities, provide support to parents and carers and give deaf children the chance to meet outside of school. Many also have their own social media channels.

Many families also find that learning about deaf culture, and getting involved with their local deaf community, can be a reassuring and empowering experience. Search for deaf clubs and societies in your area to connect with deaf adults. You can also learn about deaf culture online or by watching TV shows like BBC SeeHear. Another great resource is Lumo TV, a streaming platform run by and for the deaf community. It's full of programmes and short films showcasing different experiences and perspectives from the deaf community.

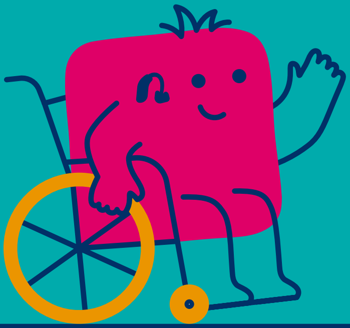
Find local groups on our website at **ndcs.org.uk/local-groups**, or use Facebook to search for events and groups in your area.

Some parents have asked…

"What kind of support are we going to need and how available is it in our area?"

"Who else will be involved?"

"Where can we go to get the right support and connect with other people?"



"What's a Teacher of the Deaf?"

Other parents have said…

> Look for a local deaf children's group in your area. They provide peer support for both parents and children. Ensure you get support from sensory support, including a Teacher of the Deaf (ToD).

> If you have a ToD, they should be able to advise you about what support is available in your area. We found that often the best advice and signposting came from other parents of deaf children; their experiences were so useful. It's worth joining your nearest local group to find support and to meet other parents.

> There's so much support out there from the deaf community. See if you have a deaf centre or deaf events near you. The deaf community are the real experts, and we felt so welcomed as parents of a deaf child. It was also so valuable for our son to meet deaf adults as he was growing up and helped him to be positive about his deafness.

> There is so much out there! I think the best thing to do is be put in touch with someone local who has a child a little older and they will be able to help you navigate the local resources available. In Gloucestershire we have a parent-led Facebook group and there are resources that everyone contributes to, to share help and info with other parents.

> The support you get will depend on where you live and your child's age and level of deafness. You might have to ask to get the following support.
>
> - regular, accurate hearing tests to keep an eye on their hearing levels and ensure good access to sound
> - advice on benefits like free carer's tickets or DLA
> - support for starting nursery or school
> - info on charities that can help
> - goals to work towards and speech therapy you can do at home yourself
> - good technology and advice. (If nobody has told you about radio aids, ask!)

> See if you can be referred to a ToD. My son has one and she's his biggest support.

> Our ToD has been great and the support has been amazing from them and the audiology department.

Getting support from friends and family

Remember that the people who care about you would like to offer you help and support. Ask them when you need help, not just for your baby, but for you too – there will be other times when you can repay the favour.

If you're finding your child's medical appointments overwhelming, ask if a friend or relative could come along too. Bringing your child's grandparents to appointments can be a great way for them to learn more about childhood deafness and how they can support their grandchild.

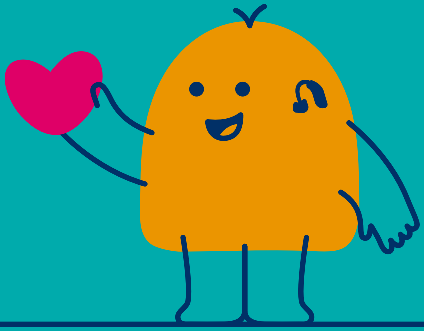
Having a child with hearing loss affects the whole family, so talk to your relatives and friends about how you're feeling. Encourage your other children to tell you how they feel, and make sure they feel included in their deaf brother or sister's life. Young children may not understand where you're going during their deaf sibling's appointments, which can lead to resentment and jealousy. It's not always easy, but try to find time to spend one-on-one with your hearing children, too.

'Me and my deaf brother or sister' is an activity book for hearing siblings of deaf children. Order or download a free copy on our online bookshop at **ndcs-bookshop.myshopify.com**

Some parents have asked…

“How will I tell friends and family about my child’s hearing loss?”

“What does this mean for our family?”



Other parents have said…

> Hearing loss is nothing to be ashamed of. Get your tribe involved to support and help make the journey fun.

> After my son's diagnosis, I bluntly told my family that he is profoundly deaf but we should all still talk to him and treat him as normal. My parents' response was that he's still the boy he was yesterday, and his diagnosis doesn't change this. Telling people can feel overwhelming but once you do it and get all the support, you feel like a weight has been lifted.

> I think a matter-of-fact approach is best. There is no shame in a diagnosis. Also, your child will pick up on your attitude to their hearing loss and it will shape their own attitude. So never try to hide it, be matter-of-fact, be open to questions, help people learn about deafness and always be proud. Our children are perfect just the way they are. Hearing loss will never change that.

> I told everyone that she is deaf, she has hearing aids, but she is still just a little girl. She needs to be treated slightly differently but it's only a minor adjustment from them. I told family and friends that they don't have to learn sign language, although learning some simple signs would be amazing. It's more important to learn the basics of deaf awareness, like making sure they're looking at her when they talk, making full eye contact and getting her attention before starting a conversation. We remind them to repeat themselves in case she doesn't hear what they're saying. I think the hardest thing to get through is that being deaf doesn't mean she can't hear anything at all.

> Just be factual and ensure you advocate for your child in how people need to communicate and what environments are easiest for them to be in.

7 Education

Some parents choose a school for their child before they're even born. This could be because of their religious beliefs, because a school has a good reputation, or because the child's older siblings are already enrolled at a school.

Finding out that your child is deaf might challenge the plans you had in place. Try to keep an open mind. Even if you think you've already chosen the right school for your child, it's always good to visit any other options to make sure you know what's available. If your child has a Teacher of the Deaf, they can support you with school choices when the time comes.

Most deaf children go to their local mainstream schools. Some children go to mainstream schools with resource bases, where deaf children can get specialist support. (These are sometimes called resource provisions, deaf hubs, or hearing-impaired units.) A small proportion of deaf children go to deaf schools, special schools, or independent (private) schools. Some deaf children are home-schooled instead.

It's worth being aware that deaf children who are privately educated or home-schooled may not have access to a Teacher of the Deaf.

If you and the professionals who work with your child think that your child would do better in a deaf school or a school with a resource base, they'll support you to find the right school.

All schools should be inclusive and think carefully about how they can make sure your child is able to learn, make friends and thrive. They should find out what your child needs to be able to learn, such as where your child needs to sit or how teachers can adapt their lessons. Working in partnership with your child's school can help them to adapt what they're doing as your child's needs and preferences develop.

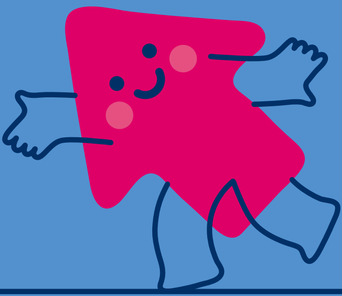
Some deaf children benefit from having additional support, such as a communication support worker (CSW). CSWs work with one or two deaf children in a mainstream classroom to make sure they understand everything that's happening in each lesson.

Some parents have asked…

“How can we get the support he needs at school?”

“What kind of school will he go to?”

“How will she get by at school?”



Other parents have said…

> My daughter goes to a mainstream school and has a part-time communication support worker (CSW) to help bridge the gap. BSL is her first language, so it was important to have a CSW even if it's only part-time.

> Let your child visit schools with you and see whether they stay by your side or feel comfortable enough to perhaps find a friend. You can arrange a meeting with the teachers, headteacher and special education needs co-ordinator (SENCO) to discuss anything. Our daughter is in a mainstream school with a specialist provision for hearing impaired students. She has access to a ToD every day. She also a weekly speech and language check-in and daily one-to-one time in a quiet space with her support worker. She just completed Reception year and so far, we wouldn't change a thing!

> My daughter went to our local village school then on to a grammar school. Neither school had ever had a child with cochlear implants before, but she's thriving.

> Choosing schools is a tough decision. I would always opt for a Deaf school first; they have an advantage of providing total communication, in speech and sign. They're also specialists in deaf education (deaf studies, visual phonics etc) and will often have audiology and speech and language therapy on-site. Technology can fail but language doesn't. Also, if you opt for a deaf school first, it's easier to transition to a mainstream school in the future. If you choose mainstream first and later decide a deaf school may be best, prepare for a fight with your local authority. It can take years for the transition to happen, which could hinder your child's education. That said, I think the parent will know what's best for their child. Don't always go with what the professionals recommend; as a parent, you have the final say. If you can, try to speak with deaf adults to see what they think; they've had lived experience.

> Every time we asked a therapist or our ToD about which school our child should go to, they'd tell us, 'Whatever school is right for them.' It made me panic about making the wrong choice! But they also told us to see as many options as we could and not rule anything out. They gave me a checklist of things to think about, such as, 'What is the flooring made of?' 'Are there soft furnishings to dampen loud echoey noises?' 'Where does the teacher stand?' I was told to visit multiple times.

> My advice is to speak to your Teacher of the Deaf. My son has an education, health and care plan (EHCP) and attends a deaf provision. Since being there he has now started to learn BSL, which will absolutely help him in the future.

> It can be scary to think about the future. When the time for school comes, you can look at the best option for your child, whether mainstream, a deaf hub or a deaf school. My child is thriving in our catchment secondary school; they have a great special educational needs provision. I know of other children who need a deaf school and others a school with a resource base.

> Let your child visit schools with you and see whether they stay by your side or feel comfortable enough to perhaps find a friend. You can arrange a meeting with the teachers, headteacher and special education needs co-ordinator (SENCO) to discuss anything. Our daughter is in a mainstream school with a specialist provision for hearing impaired students. She has access to a ToD every day. She also a weekly speech and language check-in and daily one-to-one time in a quiet space with her support worker. She just completed Reception year and so far, we wouldn't change a thing!

> It depends on the individual. I did send mine to a mainstream school. He had one-to-one support which worked well for a few years. He's now 10 and is now in a mainstream school with a deaf provision. He's doing really well there.

> With the right support, your child can go to a mainstream school if you wish. You're not limited to special educational units. When my son was born, I put his name down for our local mainstream Catholic school (which I always had my heart set on). When he was identified as deaf, I put him down for our local mainstream school with a deaf base. He's now 3 years old and after multiple visits to both schools, we decided to send him to the school with the deaf base. He'll be in a mainstream classroom, supported by the specialist base staff. I'm at a point where it doesn't really matter what school he goes to, the important thing is that he gets the support he needs to reach his full potential. Don't worry about what kind of school your baby will end up at, that's a minute detail. Visit a variety of schools and make your decision based on what support your child needs at the time and what the school can offer.

8 Thinking about the future

Families come in all shapes and sizes – and so do the challenges they face. There is no ‘right way’ to parent a deaf child. Our goal is to help you raise your child with confidence, compassion and a sense of belonging.

As your child grows, their needs and experiences will change. You may need to revisit decisions you made earlier or change your parenting style. Try to keep an open mind, allowing your child to define their own deaf identity.

Some parents have asked…

“How will our life change?”

“How will I manage?”

Other parents have said…

> I hated being told early on that everything would be OK, but in fact, it's been more than OK. My daughter is flying and loving life! There are challenges, but my daughter has so many opportunities and she is resilient and knows how to persevere. She is more sensitive to other people and any challenges they have. Everything she achieves – from getting into grammar school to music exams and maths Olympiads to synchronised swimming competitions – all seem slightly sweeter knowing the challenges she has overcome. You manage by keeping fighting for your kids, for the best for them, for inclusion, for the right care and equipment, by educating yourself and teaching the professionals if needed!

> Emotionally, you may need support and someone to answer your questions, but enjoy your time with them. You don't get it back.

> I feel lucky to have my deaf daughter. I feel like she chose me to be her mum.

> I managed by doing – stepping up and being her voice, advocating for her where she couldn’t advocate for herself, learning some BSL, looking into what she might need (both now and in the future), and finding a group with other families like ours. The National Deaf Children’s Society website has lots of information to help. Also, make sure you have someone you can confide in when you feel emotionally drained and need to offload. It’s hard work, but when they succeed, it’s so rewarding.

While every child’s needs and abilities are different, you can expect your child to enjoy a childhood that’s as happy and full as a hearing child’s – playing, making friends, enjoying sports and leisure activities, achieving at school and having fun! They might need a bit of extra support or a few adjustments, but with the right support, there’s very little a child with hearing loss can’t do.

There may be times when you and your child need to advocate for the adaptations they need and the access they deserve. We’re here to support you and your family every step of the way. We can help you understand and champion your child’s rights to education, employment, healthcare, and financial benefits.

As your child grows and becomes more independent, they might choose to learn to drive, travel, work, study and eventually pursue a successful and fulfilling career. Deafness shouldn’t be a barrier to your child doing what they really want to do. With the right support, most life, education and career options will be open to your child, so encourage them to aim high!

Some parents have asked…

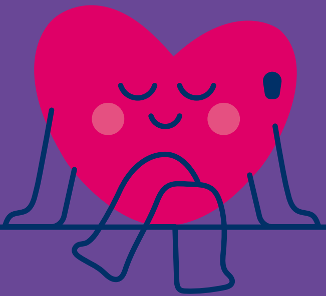
"Will my child lead a 'normal' life?"

"How will this affect her long-term?"

"What does this mean for my child's future?"

"Will their life be hard?"

"What will his life look like?"



Other parents have said…

> These were my exact first questions. I was often told, 'She'll adapt,' with no real explanation of what that meant. When her hearing suddenly deteriorated from unilateral loss to bilateral loss, we were furious we had been left scrambling to help her communicate at the age of 3 because we'd been left to 'adapt'. But instead of being angry we put that energy into her, focusing on advocating for her and ensuring she is given every aid and support available to her. We've fought for speech and language therapy, physiotherapy, vestibular assessments, an education, health and care plan (EHCP) and the right school, all to make sure she gets to experience the same things as her peers and isn't left behind. We still don't know what the future holds for her, but she is strong and brave and we hope we've given her the tools she needs in life (so far) to continue being her amazing self. The future can be changed, it's not set in stone!

> Don't worry about the future. What happens will happen and you will deal with it and cope with it and even better so will your child. They are more resilient than we are!

> It may take time to discover what is ‘normal’ for them in regards to what they can access, their personal interests and preferences. I would suggest getting involved with your local deaf children’s group, so that both parents and children can start to connect with the deaf community, get advice from others and take part in deaf-friendly activities. Ensure you ask for help and support, that they have a Teacher of the Deaf. See what training can be given to any education establishment. Most of all, don’t panic!

> I have complete confidence my daughter’s deafness is not going to affect her future in anything but positive ways. Putting in the work in the early years to ensure they aren’t ever left behind is so vital. I honestly think the world is her oyster! She’s 13 now and it’s been a complete rollercoaster with hearing aids, deteriorating loss, cochlear implant failures and schools not quite getting it right. However, she is now at a fantastic secondary grammar school and is flying while doing numerous activities – guides, piano, clarinet, orchestra, choir, netball, and synchronised swimming 4 times a week.

> With you as their parents advocating for them, your child will meet challenges head on. It might mean difference modes of communication or education. It might not. If the child is happy and knows no different, it's the parent's expectations that have to change and that can take time to accept. They will still have friends, still have a job, still learn and play and laugh.

> My baby girl is 7 months old now. We found out she has moderate to severe bilateral sensorineural hearing loss when she was around one month old. She has hearing aids and I'm confident she's going to live a normal life. We are learning BSL at the moment and putting in so much work now, so when she is older the impact will be minimal. It has been hard work and definitely a rollercoaster but hard work pays off in the end.

> It's going to be OK.

Our information and support

We're here for deaf children and everyone who cares about them. Whatever the question or challenge, we help find a way through.

We empower families to connect and drive change in their communities, and we campaign to make sure deaf children get the support they need.

We believe nothing should hold deaf children back.

The right information at the right time

We offer free, balanced information about all aspects of childhood deafness, both on our website **ndcs.org.uk** and in our publications. Our online content and information booklets can help you learn about childhood deafness and make decisions.

Our free app, My NDCS, provides information tailored for your child's age and location.

Helping you make informed choices

Every deaf child is different, and families should be able to make decisions that are right for them. That's why we give independent support, setting out all the options, so families can make informed choices. Whether you're thinking about hearing technology, healthcare, communication or education, we want to give you the confidence to make the right decisions for you and our family.

National
Deaf Children's
Society

We're the National Deaf Children's Society, the charity for deaf children with any level of hearing loss.

Helpline
0808 800 8880 (voice and text)
helpline@ndcs.org.uk

ndcs.org.uk

We're always looking for ways to improve our information.

Use your smartphone's camera to scan this QR code and share your feedback on this resource.

You can also give us your feedback by emailing your comments to **informationteam@ndcs.org.uk**.

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