National Deaf Children's Society

My baby has a hearing loss

Support for parents of children aged 0–2

www.ndcs.org.uk

Our vision is a world without barriers for every deaf child.

Contents

1. I've just found out my baby has a hearing loss 5
2. Why are they deaf? 7
3. Could the diagnosis be wrong? 8
4. How will my child communicate? 11
5. What will their future be like? 14
6. What can I do to help my baby right now? 17
7. Will they struggle at school? 18
8. What support is out there for us? 21
9. Meeting other families with a deaf child 24
10. Our information and support 25

We use the term 'deaf' to refer to all types of hearing loss from mild to profound. This includes deafness in one ear or temporary hearing loss such as glue ear.

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

1 I've just found out my baby has a hearing loss

Most deaf children are born to hearing parents who have no previous experience of deafness, so for some families when they're told their baby has a hearing loss, the news can come as a great shock. The birth of a new baby brings with it a mixture of emotions, which can be equally true for parents when they find out their child has a hearing loss – you may be feeling sad, worried or angry, or relieved that you have a diagnosis.

You may feel overwhelmed at some of the choices you're being asked to make so early on in your child's life. You might be thinking about what being deaf will mean for your child, you, and your family as they grow up, and you might have lots of questions – how will they communicate? Should we learn to sign? Should they go to a mainstream school?

> **"My little boy, Preston, was born premature and was diagnosed as deaf at six weeks old and had his aids fitted by eight weeks old. He is now six years old, his vocabulary is better than mine, he is loved by all the kids in his class, and he has always exceeded [expectations] in school. He is my perfect Preston and I wouldn't change him for the world."**

We are the National Deaf Children's Society, the leading charity for deaf children. We help families give the best possible support to their deaf child every step of the way, and we are here for you.

“I never thought for a minute that she might be deaf. I felt so guilty that I might have caused it.”

2 Why are they deaf?

There may be a number of possible reasons why your child has a hearing loss. Sometimes there is no clear cause.

It's very unlikely that you could have done anything differently to change your child's hearing. There are a number of possible causes of deafness.

- Genetic – deafness can be inherited, even though there appears to be no family history of deafness. Around half the deaf children born in the UK are deaf due to an inherited gene.
- Complications during pregnancy – a number of infections can cause a child to be born deaf.
- Premature birth – babies born prematurely can have an increased risk of being deaf or becoming deaf. They may also be more prone to infections and may be given medicines, known as ototoxic drugs, which can damage a baby's hearing.
- Infection – illnesses during early childhood can also cause deafness.

Your audiologist can give you more information about tests to find out the cause of your child's hearing loss, although it's important to remember that tests will only be able to identify the cause of deafness in 40–50% of children. For the other 50–60% of cases it's not possible to find out why a child is deaf. If it's not possible to find out the cause of your child's hearing loss, it may still be helpful for you to know what didn't cause it.

3 Could the diagnosis be wrong?

Parents have told us that the shock or surprise at finding out their baby has a hearing loss can mean that, at first, they find it difficult to accept the news.

There could be reasons other than deafness to explain why a baby fails their newborn hearing screening, for example, fluid in the ear canal from the birth or temporary hearing loss, such as glue ear. After newborn screening you'll be referred to the audiology clinic for more detailed tests and as your baby gets older their hearing tests will be repeated to get a clearer picture of their hearing loss.

There are different levels of hearing loss, described as mild, moderate, severe and profound, and hearing loss can affect both ears (bilateral deafness) or one ear (unilateral deafness). Your audiologist will take you through the results of your child's hearing tests and talk to you about the sounds your child can and can't hear. As deafness can vary hugely, your child's level of hearing loss will determine what support they need.

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 need to feel comfortable with the management of your child's hearing loss, so 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 it's rarely refused if you ask.

For more information on understanding your child's hearing tests or which questions to ask your audiologist, visit www.ndcs.org.uk/hearingtests.

4 How will my child communicate?

Communication starts the moment your baby is born. As you cuddle your little one, you let your baby know, "I love you. I will keep you safe and warm." Learning and wanting to communicate is something that occurs naturally in all children. Being deaf might make this more challenging but, with the right support, commitment and encouragement from families and professionals, deaf children can learn to communicate as well as other children.

> **"One of my biggest worries after my daughter's diagnosis was that we wouldn't be able to communicate with her, have the easy conversations we have with our other children."**

With the use of hearing aids, implants and other specialist equipment, most deaf children now use their hearing to listen and learn one or more spoken languages. Many deaf children also:

- use some sign language in addition to spoken language
- use sign language as their first language and main way of communicating and learning
- use a mixture of methods.

There are pros and cons to each method and we can support you to find out what they are to help you decide what will work best for you, your child and your family.

Remember, you don't have to make a choice for life. You may want to change your approach as you learn more about your child's needs and preferences.

Find out more about different ways to communicate at www.ndcs.org.uk/communication.

How technology can help

Technology, such as hearing aids and implants, allows most deaf children to hear sound close to typical hearing levels, however, it cannot replace normal hearing.

> **"I should have asked what she would be able to hear with the right technology; a short while later I was relieved and delighted that even with severe hearing loss, her amazing hearing aids help her hear so much better than I ever dared hope for. I had no idea about the brilliant tech available and learning about this earlier could have saved many sleepless nights."**

Shortly after diagnosis, you should be contacted by your child's Teacher of the Deaf. They, along with your child's audiology team, will be aiming to get a clear picture of your baby's hearing loss and will talk to you about what you can do to support your child's speech and language development and communication.

Even with aids or implants, there will be times when your child has difficulty hearing clearly compared to hearing children, but other technology and adaptations are available to make listening as easy as possible for them. Your audiologist or Teacher of the Deaf can advise you.

Learn more about childhood deafness, including hearing technology options at www.ndcs.org.uk/childhooddeafness.

Speech and language

If you're concerned about your child's speech and language development, they might need some speech and language therapy. Speech and language therapists work as part of a team with your child's audiologist and Teacher of the Deaf to help your child and those around them to communicate as well as possible (in sign language or speech). Talk to your Teacher of the Deaf, GP, health visitor or nursery staff to ask for a referral to a speech and language therapist.

5 What will their future be like?

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 made, but on the whole there's very little a child with a hearing loss can't do.

When your child reaches their teens and becomes more independent, you'll find that they can 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! Our magazine, *Families*, features stories of deaf children and young people succeeding in every issue.

Watch our playlist of videos of deaf teenagers on our YouTube channel (visit www.youtube.com/ndcswebteam and search 'teenagers') to find out what the future could hold for your child.

“To all parents of newly diagnosed deaf children, I know the pain, anger, fear, worry and even sense of loss but one day you will realise you coped and your child is flying.”

strip

6 What can I do to help my baby right now?

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.

The arrival of a new baby is such a special time for you and your family and we are here to support you as you welcome your new addition. Get to know your new baby and their personality and spend time together as a family simply cuddling and playing! Enjoy your baby and settle them into a comfortable routine.

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 – take one step at a time. And remember, decisions you make now can be changed – what's right for you and your family now may no longer be right in a few years.

For more tips and practical ideas about how to help your baby visit www.ndcs.org.uk/developingcommunication.

7 Will they struggle at school?

With the right support, commitment and encouragement from families and professionals, deaf children can make the same academic progress as hearing children.

When your child is older you'll need to decide which type of school is best for them. At the time, this choice will be based on your child and their needs, your family, and many other factors, which will all change as your child grows, so no decisions need to be made right now.

The law requires all schools to take steps to support all children who have medical conditions and disabilities, including hearing loss, so that they can have full access to education.

No two deaf children will need the same support – it needs to cater to your child's individual needs, so before your child starts school, you can talk to their class teacher or special educational needs co-ordinator (SENCO) about what adjustments to put in place. You can also seek advice from the specialist education service for deaf children, who employ teams of Teachers of the Deaf (ToDs). The support should also be reviewed regularly and altered to adapt to your child's changing needs as they grow up.

For information on choosing a school, visit www.ndcs.org.uk/choosingaschool.

If you're ever concerned that your child's school isn't doing enough or that your child is falling behind at school, contact our Freephone Helpline for support and guidance on what to do next.

“Every bit of fear, worry and heartache are all worthwhile when they’re growing up, their speech is improving and they’re doing well at school.”

HAPPY
YEAH

8 What support is out there for us?

It's important to remember that you will know your child better than any professional who works with you. For many families, the Teacher of the Deaf is likely to be the main person responsible for coordinating early years support for the family. They will visit you to support you with any new hearing equipment, help you with communicating with your child and talk about what to expect in the future. How often they visit will depend on you and your child's needs.

> **"We had a great Teacher of the Deaf who made us realise it wasn't our fault."**

Services that can support you

You may also meet professionals in:

- health services – audiologist, audiovestibular physician, community paediatrician in audiology, ENT (ear, nose and throat) consultant, genetics counsellor
- education services – hearing impaired services (or sensory support services), Teacher of the Deaf (ToD), special educational needs coordinator (SENCO), teaching assistant, communication support worker, educational audiologist, educational psychologist, speech and language therapist
- social services – social workers who can provide practical help and advice about counselling, transport, equipment for your child, play schemes, parents' groups, sign language classes and more.

To find out more detail about each of the professionals listed above and what their roles are, visit www.ndcs.org.uk/people.

Support we can give

We have a dedicated children and family support service that works across the UK giving information and support on a wide range of topics, such as education, benefits, technology, local services and anything else related to deafness. We can help you understand your rights and options, and make sure you feel confident in making decisions that will affect your child.

Like many other parents, you'll be learning as you go – finding out more about deafness, discovering what works best for your child, trying out new approaches and adapting as your child grows. Sometimes you might find these things upsetting or confusing, but there's no such thing as a silly question – whether you're wondering why their hearings aids are whistling or why you can't seem to settle them at night, visit our website or contact our Helpline.

> **"I have been able to accept that my son is deaf, but there are still things that pop up that take me back to those feelings. It is much easier to deal with now though!"**

Looking after yourself

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. Cooking a meal, a chat over a coffee or taking your other children to school are all things that will help you and allow them to show you that they care.

Having a child with a hearing loss affects the whole family, so talk to your relatives and friends about how you're feeling, encourage your other children to show their feelings to you and make sure they feel included in their deaf brother or sister's life.

> **"We discussed what colour aids we thought he would like and tried to involve everyone in the decisions."**

Don't forget, for further support, you can always talk to your GP.

9 Meeting other families with a deaf child

When you feel the time is right, meeting other parents and families who have a deaf child and share the same worries as you can be a real lifeline. We run events for family members – mums, dads, grandparents and siblings – so that everyone can get involved. **www.ndcs.org.uk/events**

> **"One of the best things for us was when we joined a parents' support group. It was such a relief to be able to talk to people who understood what we were going through."**

You might also like to:

- join a local group to meet other families in your area. If you're unable to attend a local group, you can still join and receive local information and updates **www.ndcs.org.uk/localgroups**
- chat to other families by joining our online community (launching summer 2018)
- read about other families' experiences of having a child with a hearing loss in our *Families* magazine at **www.ndcs.org.uk/magazine**
- follow us on Facebook at **www.facebook.com/NDCS.UK.**

10 Our information and support

Joining the National Deaf Children's Society gives you access to a wide range of services that can support you at different stages of your journey and your child's development. We want to do all we can to give you the confidence to support your child and make decisions.

The right information, at the right time

We offer free, balanced information about all aspects of childhood deafness, both on our website **www.ndcs.org.uk** and in our publications. Our online content and information booklets can help you make some of the difficult decisions you'll be faced with.

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 about how they want to communicate, or which type of hearing technology is best for them. We never promote a particular approach, and we're always clear about the impact it will have on a child's life.

Support when you need it

Any questions? We're here to help.

Freephone Helpline: 0808 800 8880

helpline@ndcs.org.uk

www.ndcs.org.uk/livechat

About us

We're here for every deaf child who needs us – no matter what their level or type of deafness or how they communicate.

Visit our website **www.ndcs.org.uk** or contact our Freephone Helpline to find out how we can support your child at every stage of their life. Join us for free and you'll be able to:

- download or order our free information
- come to our events
- be a part of our online community
- borrow equipment through our technology loan service
- read about other families' experiences in our quarterly magazine and email updates
- access support.

National Deaf Children's Society

We are the National Deaf Children's Society, the leading charity for deaf children.

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

www.ndcs.org.uk

© National Deaf Children's Society

September 2018. Review due: November 2020

Published by the National Deaf Children's Society
37–45 Paul Street, London EC2A 4LS

Tel: 020 7490 8656 (voice and text) Fax: 020 7251 5020

This publication can be requested in large print or as a text file.

For resource references or to give us your feedback email **informationteam@ndcs.org.uk.**

The National Deaf Children's Society is a registered charity in England and Wales no.1016532 and in Scotland no. SC040779. JR1252

National Deaf Children's Society