



Microtia



A Parents' Guide

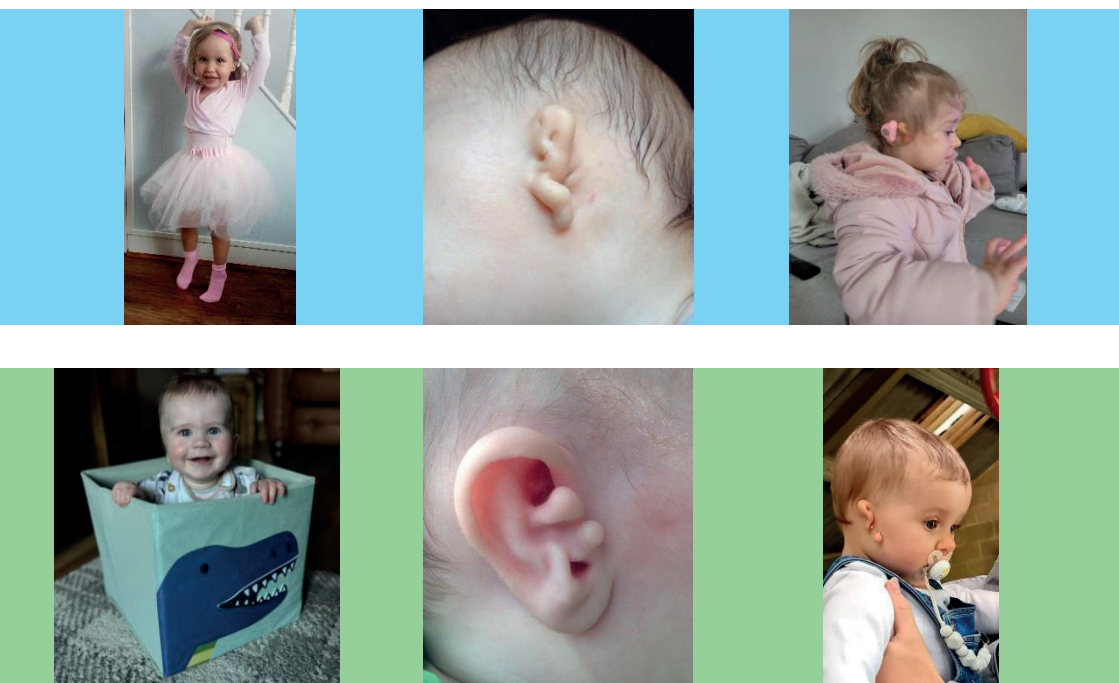


Congratulations on the birth of your baby!

Congratulations on the birth of your baby! Becoming a new parent is both one of the most wonderful and challenging times of your life. Discovering that your baby has been born with a medical condition and a visible difference may leave you feeling overwhelmed. Gathering accurate information about your child's condition, treatment or management during these early stages, can help you

feel less anxious as you begin to understand more. However, try not to overburden yourself with concerns for the future and focus on the present and what you need to do now to support you and your baby. Please know that you are not alone. This leaflet has all the information, advice and resources you will need to guide you through these precious early days.





What is Microtia?

Microtia (Greek for 'little ear') is a malformation or misshape of the external part of the ear (pinna) and can vary in severity from the ear being smaller than expected to varying degrees of absence of the outer ear. In some cases, a smaller or incomplete ear canal and/or hearing apparatus may be present or missing altogether (atresia). Microtia is frequently accompanied by atresia because the outer ear and the ear canal develop together during pregnancy.

Microtia is a rare condition affecting approximately 1 in 6,000 babies. Research suggests that it seems to affect more boys than girls and affects right ears more than left. Unilateral microtia (one ear) is more common, however, approximately 1 in 10 children born with microtia will have bilateral microtia (both ears).



First Questions

How did this happen?

Is this my fault?

What was I doing around the time the ears developed?

What are the possible causes?

How will my baby develop?



Questions like this are only natural as a new parent and it is hard not to look back on the 9 months of pregnancy to search for a reason. Microtia usually occurs in the womb approximately 8 weeks after the baby is conceived - which is when the ears start to develop. The most popular theory for the cause of microtia is an interruption of the blood supply to the area which will form the ear during this time. Nothing you would have done during this period would have influenced this.

A link to twin pregnancy, diabetes, bleeding in early pregnancy, genetics and environmental factors

are all further theories to the cause of microtia, but there is currently no medically proven link. Each case should be assessed on an individual basis.

Whatever the reasons are for microtia, providing there are no other health conditions, and the hearing is addressed, it is important to remember that your baby has the same needs as all babies. They will continue to eat, sleep, cry, and need plenty of cuddles! If you try to look too far into the future at this stage you may feel apprehensive. Instead, try to take each step as it comes and enjoy your baby at that particular stage. Use the support and resources offered along the way and always ask for help and advice if you are concerned.



"My husband and I had never heard of microtia before, and our two older girls were born with 'normal' ears. At first, we thought his ear was just a little scrunched up and it wasn't until the doctors told us there was something wrong so to speak; we were obviously worried, and I felt very guilty that it was my fault in some way. However, after seeing the audiologist and the specialists, we now embrace his little ear, and to us it just makes him that little bit more special. Using the forums and resources online is fantastic and are there to be used."

**Hannah Mason; member of Facebook Microtia Mingle UK
and mother to Milo (unilateral microtia).**



Hearing Loss

Can my baby hear me? Does microtia mean they are deaf in that ear?

Depending on which part of the ear is affected, your baby will have some degree of hearing loss. With microtia, the outer and the middle ear can be impaired, and the ear canal may also be very narrow, blocked or absent (atresia), leaving no way for sound to pass through. However, in most cases the inner ear remains healthy giving some options for restoring the hearing available. When microtia is unilateral, there is usually hearing in the other ear but in bilateral cases your baby will need some form of hearing aid to assist as soon as possible. Nevertheless, hearing aids can be useful for babies with any level of deafness.

Hearing Tests Available

Shortly after giving birth your baby should be referred to your local audiology department for further assessments. Your doctor, paediatrician, midwife or health visitor will be able to refer you.

ABR (Auditory Brainstem Response)

ABR is normally the first test carried out and requires your baby to be asleep so that their brain is in a restful state. A series of clicking and tonal sounds (beeps) are played through headphones or earphones when there is an ear canal. Three small sensors are placed on the baby's head and connected to the computer equipment. The brain responds to these sounds and the brain activity is recorded via the computer as the sound travels through the outer ear as vibrations. When it reaches the inner ear (cochlea) the sounds

are converted into an electrical signal. This travels along the auditory (hearing) nerve to the brain where it is processed into recognisable sounds.

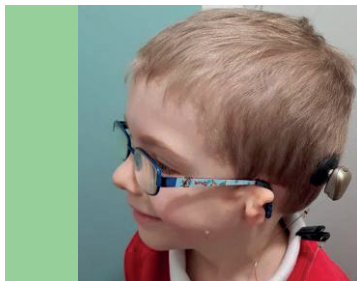
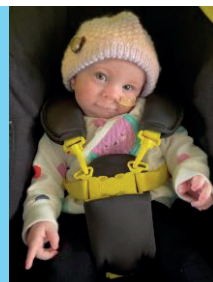
Whilst you might feel this is very intrusive for your new baby, it is important to complete it in order to ascertain their level of hearing and how to help further.

VRA (Visual Response Audiometry)

VRA is suitable for children from six months or when sitting up to about two-and-a-half years. Sounds of different frequencies and loudness are played through speakers. When the child hears the sound, they will turn their head and a visual 'reward' is activated, such as toy lighting up or a puppet.

You will probably be asked to return for further monitoring every few months. As your baby gets older and develops more skills the type of testing will reflect this.





Hearing aids - what is available?

Microtia can cause conductive deafness. This is where a sound is unable to pass efficiently through the outer and middle ear to the inner ear (cochlea) and the auditory nerve. Depending on the level of microtia your baby has (i.e. unilateral or bilateral) and based on the initial hearing test results, your audiologist may want to offer your baby a hearing aid.

A bone conduction hearing aid works by conducting sound through the bone in the skull. When there is noise, the sound is transmitted directly from the vibrating part of the bone conduction hearing aid through the skull to the inner ear, missing out the outer and middle ear.

This hearing aid usually consists of a bone conductor unit fitted to a soft or hard headband. The headband holds the conduction aid close to the bone near the microtia ear. In bilateral cases, often two aids can be offered on one band. The aid can either be a conventional bone conduction aid or a bone anchored hearing aid (BAHA) that can later be fitted to the head via an abutment or magnet. Please see the **Possibilities for the Future** section on pages 16-18.



Learning and Speech Development

As part of your ongoing care from your local audiology department, you should be allocated a teacher of the deaf (TOD)/hearing impairment teacher. TOD's are qualified teachers who have taken further training to teach deaf children. They provide support to deaf children, their parents and family and to other professionals who are involved with a child's education. Initially they will complete termly visits at home to monitor your baby's development at home, nursery or pre-school and then later they will visit your child during school term time.

Some TOD's have specialist training to work with very young children. For many families, the child's TOD may be the main person responsible for coordinating the early years support service for the family. They can and often do play an important role in helping parents to support their deaf child.

Your TOD will monitor your baby's learning and speech development and if necessary, can refer you to a speech therapist for further help. Please bear in mind that it is not just children with deafness that may require additional speech therapy.

Please note: In Scotland TOD's are known as visiting teachers for the hearing impaired (VTHI) and their practice is carried out slightly different from other areas of the UK. The frequency of visiting depends on the individual child's situation/need, in negotiation with the family and is also dependent on intervention from audiology.

Communication at Home

There are some very simple things you can do to help your baby in those early years to develop and maintain good listening and communication skills, here are a few examples:

- Always tell your baby where you are if you cannot be seen.
- Position your baby so that they are in the optimum position for listening. Facing the sound source if bilateral or unaffected ear towards source of sound if unilateral.
- Use a parent facing buggy when out so your baby can see you communicating and locate where your voice is coming from.
- In unilateral cases, position the car seat so the unaffected ear is towards the driver/main communicator.
- Background noises such as radio and television can cause sound disorientation so create quiet surroundings for play and reading to ensure the best possible listening environment.



- If you suspect your child has an ear infection in the hearing ear, visit your family doctor (GP) promptly.

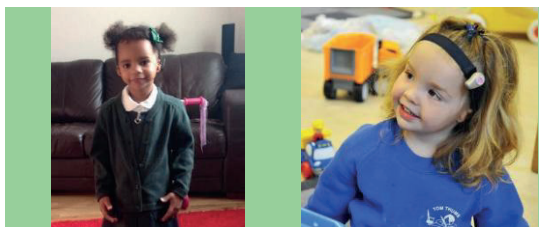
Speech and Language Therapists (SLT)

SLT's offer support and advice to parents of children with any type of communication needs, including deaf children. They help children to develop their communication skills. This can be in sign language or in speech. Some SLT's specialise in working with deaf children – these specialists are not available in every area.

Babies must understand words before they can start to talk. You can help your child learn by holding them close, making eye contact and talking to them from as soon as they are born. They will look back at you and begin to understand how conversations work; even making 'baby noises' will teach your baby useful lessons about listening and the importance of words and taking turns in a conversation.

Some children find it hard to learn what words mean or struggle to use words or put them together in sentences. Others may use long sentences but find it hard to make themselves understood or have difficulty pronouncing certain sounds. If at any point you are concerned about your baby's

speech development then please contact your TOD, doctor (GP) or audiologist for a referral and further advice.



Special Educational Needs Co-Ordinator (SENCO)

If your baby attends a nursery or going forward, a pre-school and then school, the nominated SENCO will co-ordinate additional support needed for your baby together with the TOD.

The SENCO will coordinate and help to develop effective ways of overcoming any barriers to a child's learning and ensure that they receive effective teaching through assessing the child's needs.

Please note: In Scotland, the assessment of your child's support needs would be made within the multidisciplinary setting of a Child Planning Meeting (CPM) under the Getting it Right for Every Child (GIRFEC) framework.



Tests/What Happens Next?

During the first two years you might have what seems to be a never-ending series of hospital appointments. Whilst these can be a difficult and worrying time for you, they are full of important tests and information to ensure your baby receives all the help they need. A referral to a paediatrician can help you to oversee and co-ordinate any additional care required. This can be carried out either during your hospital stay or your postnatal hospital care via your doctor or midwife.

Hearing Tests

A referral to your local audiology services is essential to ascertain your baby's type of hearing loss and hearing levels. Your newborn's hearing test may result in an automatic referral due to the nature of the condition or your paediatrician may make the necessary referral arrangements. If this doesn't happen, please ask your doctor to refer you.

Initial Tests

The majority of children with microtia have no other medical problems. However, microtia can be a sign of a syndrome. A 'syndrome' means a collection of features that commonly occur together and that doctors recognise as being related. The following tests are generally considered to be the priority initial examinations needed to assess whether your baby's microtia is part of another syndrome. It will then help your paediatrician to find out

what further testing or treatment may be needed depending on the results:

- **Kidney Scan**
- **Spinal X-ray** - Vertebral anomalies are more common in children with microtia however X-rays are only indicated if they will change the medical management.
- **Heart Ultrasound (echo).**
- **Eye Test** - Hearing and eye complications are often linked so regular eye checks can monitor any potential problems.

Further Tests that may be offered:

CT Scan

A CT scan can offer an insight to how much of your baby's ear has developed on the inside and can help with making further decisions regarding hearing aids. These tests involve some radiation so therefore offer a small but definite risk. Doctors therefore prefer to only order a CT scan when it will influence treatment, and it will often depend on the grade of microtia and the individual hospital's policy.





Plastic Surgery Referral

You may be referred to a plastic surgeon to discuss the future decision of having the ear(s) cosmetically reconstructed. This process isn't generally considered an option in the UK until a child reaches the age of 9.

Genetic Tests

You may be given the choice to have genetic testing. These tests may provide a sense of relief from uncertainty of further problems and help you make informed decisions about managing your baby's future health care; in particular when there is other syndrome symptoms detected. However, they can be intrusive and are often inconclusive. In most cases microtia appears to be a randomly occurring event that happens during early development.

Please note: Every hospital will have different policies and procedures so the above are guidelines only. Please speak to your health professional if you would like further information or a referral.

"Our daughter, Olivia was born in 2007 with right sided microtia. We are very proud parents, who have really enjoyed watching her grow and develop. The last 7 (and a very important half!) years have flown by. Olivia is a very beautiful, caring young girl. She loves to sing, dance and swim and makes new friends wherever she goes."

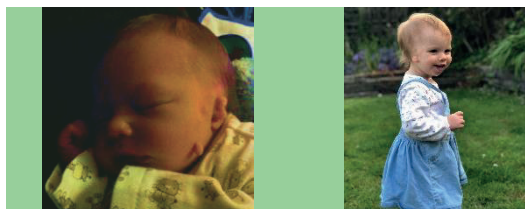
**Duncan & Samantha Maskell;
members of Facebook Microtia
Mingle UK and parents to Olivia,
(unilateral microtia) and Annabelle.**



Telling Others

Introducing your baby to the outside world and being able to talk confidently and openly about their microtia may be hard at first. You may want to shelter and protect your baby from others' opinions or comments, or you may find that you have an overwhelming urge to tell everyone you come into contact with before they notice or question it. When telling family and friends you may find it easier to do so over the phone or to include some basic information with the birth announcement. This may also avoid any initial surprise or awkwardness when they are meeting your baby for the first time and may ease your own worries too.

When out and about you may be aware of the odd double take, and you may be more sensitive at first and be on the alert ready to defend. People can be curious when they see something different, and this is a natural reaction. If you are faced with a stare that makes you feel uncomfortable you could always approach that person and talk to them about it. Or by simply catching their eye and smiling back, you will probably find they will either look away or start a conversation.



You may also have instances when people ask you about your baby's ear, especially children. In most cases a simple explanation is often all that is needed to satisfy their curiosity followed by finding a common ground to continue the conversation naturally.

For example:

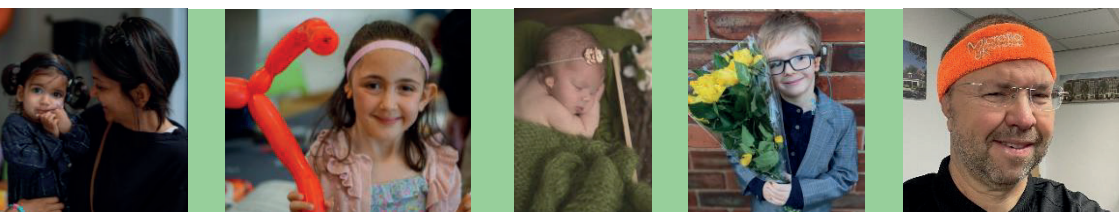
"She/he has a little ear. They look different, don't they? It's just the way she/he was born. She/he has a bike just like yours and rides really fast."

"My daughter/son was born with a rare condition called microtia; that means she/he has a small ear; nonetheless she/he's every bit of cheeky/demanding/fun/gorgeous as any other 1, 2, 3 etc. year old."

Who can I talk to?

It will become easier in time but if you find dealing with these instances challenging, there are many support groups and organisations that can offer top tips, support and advice on this subject. Please see the **Where can I get further help and information?** section on pages 22-23.





"When I grasped Spencer and pulled him up from the bottom of the pool to look at him for the first time there was no doubt it was a shock to see his ear. But I was so overwhelmed that he was here, living and breathing and fighting fit that I was just so happy. Then there was the constant merry-go-round of having to explain to each different midwife that came, the health visitors, the GP, at baby clinic and baby classes. Not to mention breaking it to my antenatal group and all our friends and work colleagues. It was exhausting telling the story over and over and being positive and upbeat. But soon enough everyone who needed to know, knew, and we could just get on with it."

Emma Wainwright; member of Facebook Microtia Mingle UK and mother to Spencer (unilateral microtia).

(If you would like to read more of Emma's story then please go to www.microtiauk.org/lifestories).



Everyday Life

Emotional & Social Development

As a parent to a baby born with microtia you may be more aware of the different development stages and be anxious about the impact of microtia on their development. All babies will develop at different rates, and it is hard not to make comparisons to others. Providing there are no other health issues, it is important to remember that your baby will continue to develop just like other babies, but if you have any doubts or concerns then it is best to seek further advice from your health visitor or paediatrician.

What can I do to help my baby have the best start in life?

Helping your child to develop positive coping strategies in living with their microtia is invaluable. A supportive approach can help your baby to grow up to understand and accept microtia as part of their everyday life. Modeling how they can deal with others' reactions and having a confident but natural outlook to living with hearing loss and a visible difference will enhance their self-worth and resilience.

Talk openly about their condition in a natural way, and by providing positive affirmations you can minimise possible low self-esteem or self-confidence issues. Positive support from you, other family members and friends, will help your baby develop their coping mechanisms as they grow up with microtia.

Microtia is just one aspect of your wonderful baby - not his or her entire being. Raise your child as you would any other but don't deny the





existence of their microtia! This will go a long way to helping them to have a positive outlook.

When will my child notice his/her microtia?

It's generally thought that children become aware of how they are like and unlike others at two to three years of age. At this stage they are just beginning to acknowledge, observe and express differences and other things may also be mentioned e.g. glasses, colour hair/eyes etc. When they begin to notice that their ear(s) are unlike those of other children they will naturally comment and ask questions. Their friends will be curious too. Children are very accepting of new information, and a simple reply is often all they need. Leave the door open for them to ask some more.

Finding support from others

Microtia UK was formed from a Facebook support group called 'Microtia Mingle UK'. This is a group for children, families and adults affected by microtia and atresia. It has a continually growing community offering a wealth of help and advice to help you through those early years.

If you would like to meet another family with microtia, Microtia UK would love to help you get in touch. Please email us directly with your details and we can get you in contact with a family who lives close to you.



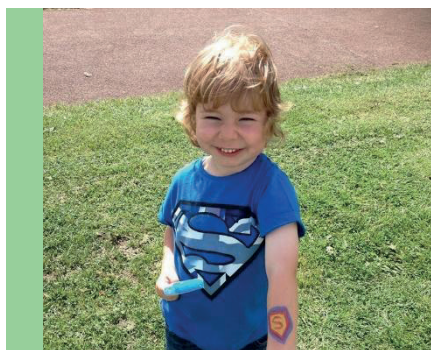


Your baby will have the same needs as all babies and there is no reason why you can't use all the support tools and help from your family and friends just as you planned during pregnancy. Remember, most of your baby's continuing behaviour and development is due to being a baby rather than the microtia.

If you or your child are struggling to cope, or if psychosocial difficulties arise, don't be afraid to ask for psychological support through your GP, health visitor or paediatrician. There are also many other support and help organisations in our **Where can I get further help and information?** section on pages 20-21.

"When my boy was born, I felt very uneasy taking him out in public, I felt everyone was looking at him and judging me. I felt guilty it was something I had done wrong in pregnancy. With help from a one-off session with a counsellor and support of family and friends, I've come to realise it's just an ear. Lots of kids are born with awful illnesses that need constant medical intervention. I'm grateful that my boy is healthy. We might have some issues to overcome as he gets older, but he is a happy, bubbly, confident and popular little boy and is beautiful inside and out! We are very lucky parents to have such a special son, and we tell him so every day."

Lesley Simpson; member of Facebook Microtia Mingle UK and mother to Archie (unilateral microtia).

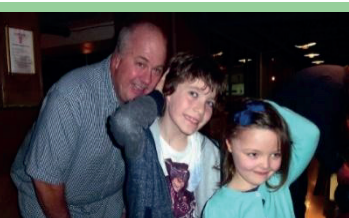


Possibilities For The Future

There are several different treatment options for the microtia ear(s) and there are many medical professionals and support groups that can help you think through the options as your child grows and develops. Try not to feel pressured into making a decision one way or the other when your baby is so young.

Leave Alone

During your baby's formative years, it is important to encourage them to embrace their differences and help them to feel confident in themselves. By being open about the options available to them, it will help them to make informed choices about their microtia ear(s). Some may feel that reconstructive surgery is the right choice for them whilst others may prefer to leave alone. It is important not to presume that your child will want to make any changes.



Prosthetic Ear

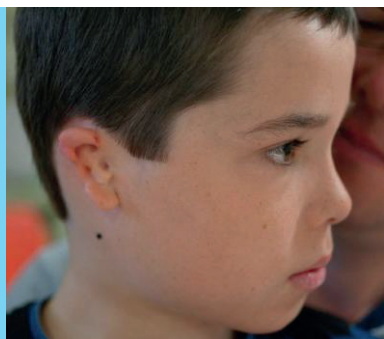
Two surgical procedures place implants into the mastoid bone. The first stage places the implants, and these are left to integrate/knit with the bone. After 4-6 months an abutment is placed on the top of the implant to perforate the skin. Magnacaps are placed on these abutments so that magnets within the ear prosthesis attach to them.

An adhesive ear prosthesis does not require any surgical procedures and is essentially a glue applied to the under surface of the ear and this attaches to the skin. The disadvantage with this is that the adhesive can fail, and the ear prosthesis may fall off or the adhesives may need to be plied several times a day.

A specialist surgeon would determine if they can create an ear that will fit over the existing ear or if the ear has to be removed. The surgery is less invasive than the Medpor or rib graft techniques. Some choose the prosthetic option as a go between whilst waiting for reconstructive surgery.



Possibilities For The Future: Reconstruction



Medpor Ear Reconstruction

Reconstruction with the synthetic high density porous polyethylene (HDPPE) implants is possible. Various brand names are available including Medpor, Surpor and Omnivore. Because no rib is involved surgery may be performed as early as 3. If only one ear is involved, the HDPPE framework is sized to match the non-affected ear but is created slightly larger in younger children so the ear will be adult sized and over time the non-affected ear will grow to a similar size. This framework is then covered by a flap of fascia from the temple and skin grafts.

Ear Reconstructive Surgery with Rib Graft

This is highly specialised cosmetic surgery and best undertaken by experienced surgeons working in a team with otologists.

It involves 2 to 3 operative stages, about 6 months apart. This procedure involves creating a skin pocket at the site of the ear. Small sections of the patient's lower rib cartilage are then carved and wired together to produce a detailed ear framework which is then inserted into the pocket. A gentle suction is applied to enable the skin to stretch over the framework. After six months the ear can be released from the head and a small piece of cartilage and skin graft is inserted behind it to maintain projection. Generally, the procedure will not be considered until at least the age of 9. The rib cartilage needs to be of a certain size to be able to shape a new ear with it and in unilateral cases, the other ear would have reached its adult size and can be used as a comparison when creating the new ear. Ear reconstruction can seem a scary prospect during those early years. All types of ear reconstruction involve a risk of complications such as implant exposure or delayed healing. The doctors looking after your child should discuss these risks.



Possibilities For The Future: Hearing

Bone Anchored Hearing Aids

Bone conduction hearing aids are often referred to as BAHAs. When your baby reaches school age the bone conduction aid can be changed to a bone anchored aid through a surgical procedure which implants a titanium screw into the skull behind the ear. The bone anchored aid then clips on to this abutment allowing sound to be conducted through the bone and more directly to the inner ear. Children have been shown to benefit from a bone anchored hearing aid as this often results in improved sound quality. It can also be very comfortable to wear compared to bone conduction headbands. There can be a risk of surgical complications, such

as infection, and the abutment area needs to be kept clean on a regular basis.

Magnet Anchored Hearing Aids

This works in the same way as the BAHA, but the processor is attached to the skull via a magnet. The magnetic implant is placed under the skin above and behind the ear. After healing, the skin and hair look normal. An adjustable strength magnetic baseplate connected to the processor is then held in position on the head by the magnetic implant.

There are different variations of hearing aids. Please speak with your audiologist about what options are available.



Associated Syndromes

Sometimes microtia can develop as part of a syndrome such as Goldenhar, or Treacher Collins which can be further diagnosed with guidance from your paediatrician and through genetic testing.

Goldenhar Syndrome/ Hemifacial Microsomia

Goldenhar Syndrome affects the development of the lower half of the face, most commonly the ears, the mouth and the lower jaw. This condition is often referred to as hemifacial microsomia. When it is associated with other problems, particularly of the vertebrae, usually in the neck, or when there is involvement of both sides of the face together with dermoid (small cysts), it is referred to as Goldenhar Syndrome. However, it is likely that hemifacial microsomia and Goldenhar Syndrome are two ends of the spectrum of the same condition.

Treacher Collins Syndrome

Treacher Collins Syndrome is a genetic condition characterised by underdeveloped facial bones to the mid and lower part of the face and in some cases the side of the neck. Most children with Treacher Collins Syndrome have malformations of, or absent, external and middle ears.

Both syndromes can be made up of a large set of features. The main features can be assessed by carrying out tests. See the **Tests/What happens next?** section on pages 9-10. If you have any further concerns for your baby with reference to this, it is advisable to speak to your health professional.





"When Jacob was born with bilateral microtia and atresia I was so upset. We had a lot of appointments to start off with, but now it has all settled down and he is the happiest little toddler. Please don't spend all your time fretting about the future, just love and enjoy your new baby as this time is so precious and passes by so quickly. I would also recommend going on a NDCS weekend for newly identified deaf children. It helped us so much. Try to attend a mingle to meet up with other parents and children.

Good luck for the future - it is bright."

**Jodie Birch; member of Facebook Microtia Mingle UK
and mother to Jacob (bilateral microtia),
Nathan and Lily.**





Where can I get further help & information?

Organisations

Microtia UK
National Deaf Children's Society
Changing Faces
Face Equality International
Goldenhar UK
Treacher Collins Family Support
Contact a Family
Supporting Success for Children with Hearing Loss
Hands and Voices
The Ear Community

Information Leaflets and Resources

UK Care Standards for patients with Microtia and Atresia 2019
National Deaf Children's Society – Microtia
National Deaf Children's Society – Hearing Tests
National Deaf Children's Society – Family Support
National Deaf Children's Society – Bone Anchored Hearing Aids
Clinical Commissioning Policy: BAHAs April 2013
Audiogram of Familiar Sounds
Changing Faces – Handling other people's reactions
Changing Faces – Talking with your child
Changing Faces - Going to hospital
Cochlear Rehabilitation Resources
Overcome Benefits of Bilateral Hearing Loss with BAHA
Bilateral Benefits with BAHA

Children's Books

'Isaac and Lilah – A story of similarities and differences' by Liz Jones
'Isaac gets his BAHAs fitted!' by Liz Jones
'M19: The Beginning' by Adam Rood
'Bear Goes to School' by Bryony Walker
'Chelsea and her little ear make a new friend' by Simone Cheadle
'Freddie and the Fairy' by Julia Donaldson
'Flop Ear' by Guido van Genechten
'Going to the Hospital' Usbourne First Experiences



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and Oticon for sponsoring the
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Support Groups and Advice

Microtia UK
Microtia Mingle UK Support Group
Changing Faces
National Deaf Children's Society

**Please speak to your GP or Health Visitor
if you are feeling depressed**

Non-Executive Advisors

Alex Seifalian Professor of Nanotechnology and
Regenerative Medicine (UCL)

Michael Markiewicz Consultant Paediatrician
(Chelsea & Westminster Hospital)

Neil Bulstrode Consultant Plastic Surgeon and Lead Clinician for
the Department of Plastic Surgery (GOSH)

Ken Stewart Consultant Plastic Surgeon and Lead Clinician for
Plastic Surgery (NHS Lothian)

Catriona Moffat Chartered Clinical Psychologist (NHS Lothian)

David McAlpine Professor of Auditory Neuroscience (UCL)

Walid Sabbagh Consultant Plastic Surgeon (Royal Free Hospital)

Greg O'Toole Consultant Plastic and Reconstructive
Surgeon (Royal Free Hospital)

Tony Sirimanna Head of the Audiology, Audiological Medicine
and Cochlear Implant Department (GOSH)

Celia Flatley-Priddey Adult with Microtia

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