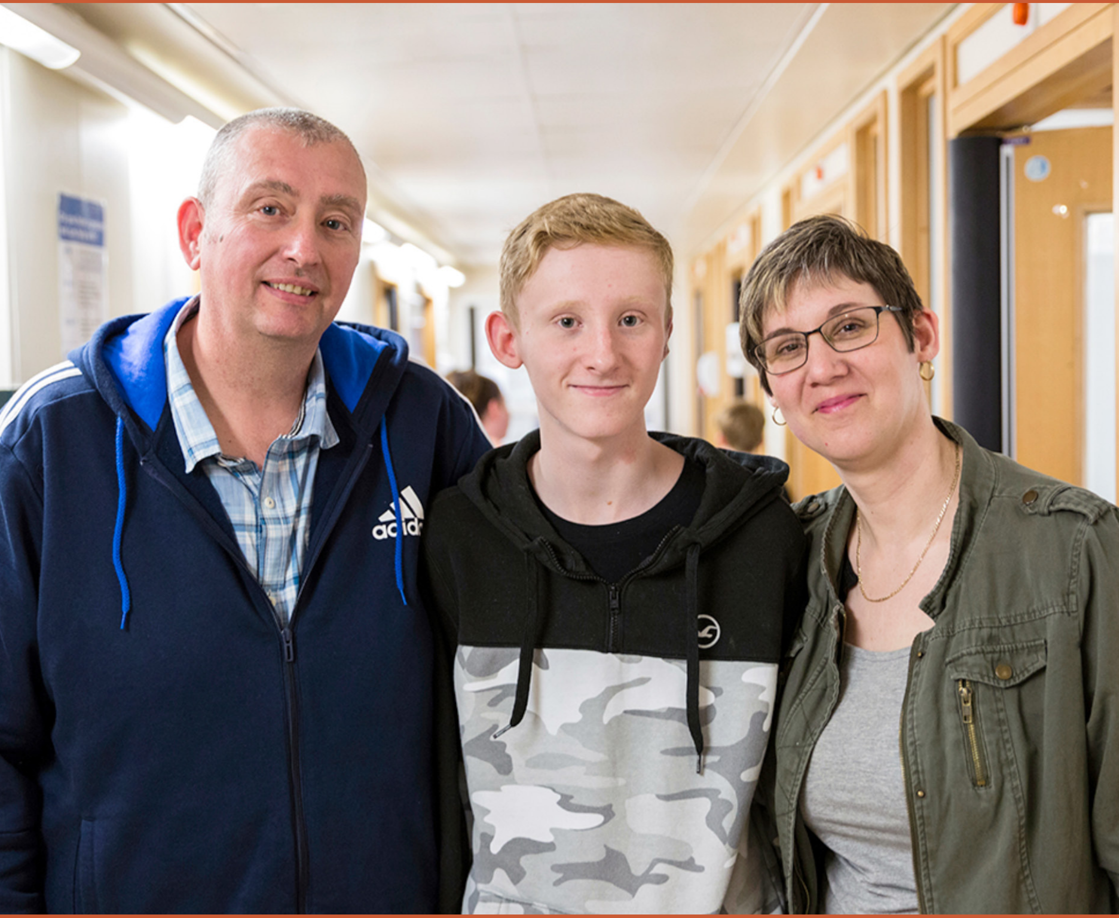
Reconstructive Surgery for Microtia

Your Child and You



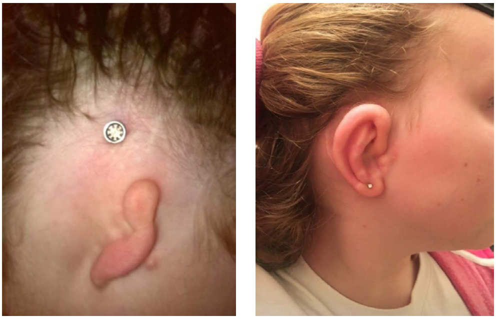
Microtia UK

What is this leaflet about?

Parents have reported that making decisions about their child's treatment for microtia, including whether and how to construct an ear shape, can be difficult and stressful. This leaflet has been created to help parents/carers who are in this situation. It aims to provide information about surgical options, advice on how to support your child's decision-making, and tips from other parents who have previously been in this situation.

It has been created by Microtia UK, in collaboration with the Centre for Appearance Research at the University of the West of England, parents of children with microtia, and Dr Catriona Moffat, a clinical psychologist and Mr Ken Stewart, a consultant plastic surgeon, who are both based at NHS Lothian.

Please note that throughout this leaflet we use the term 'reconstructive surgery' to refer to a procedure that aims to create an external ear shape, but we appreciate that some people prefer to use the term 'ear construction surgery'. Also, this leaflet does not cover surgery or other hearing aid options to restore hearing for children with microtia – please see the end of this leaflet for further information and speak to your audiologist or get a referral through your GP if your child's hearing has not been assessed.



Before and after Rib Cartilage Reconstruction

What options are available?

The surgical and non-surgical options available include:

No intervention

Some parents and children feel there is no need for intervention to change their appearance. Some report that microtia has no negative impact for them and some actively embrace and celebrate their unique features. Others may be considering change but are unsure about having surgery. Surgery can still take place later if these feelings change.

Prosthesis

A customised silicone ear prosthesis can be made to suit the child's ear shape and colour. They are attached to the head either by adhesive (a non-surgical option) or bone anchored implants, which are inserted during a surgical procedure. This option requires the prosthesis to be removed every night at bedtime.

Rib Cartilage

This option involves surgically removing rib cartilage from the child and using this to carve a new ear framework which is then placed in a skin pocket at the correct position. This is typically performed when the child reaches 9-10 years of age.

Polyethylene Implant

This option uses artificial implants instead of the child's own rib cartilage to create the ear framework. This technique, which still requires surgery, requires a 'flap' of tissue from under the scalp and skin grafts to cover the implant.

Tissue Engineering

Many families ask about the iconic 'ear on the back of the mouse'. Tissue engineering is a scientific method by which human tissue parts can be constructed in a laboratory setting. This has become a reality for a handful of children worldwide in scientific studies. Many universities and a number of commercial companies are working on making this solution a readily available reality, but at present it remains a future possibility.

If you would like to investigate ear construction, speak to your surgical team about the options both for surgery and prosthetics since not all of these options might be available in your area, or deemed suitable for your child. You may wish to explore options elsewhere if those available locally do not suit your child.

It is also important to understand that all surgical procedures involve a degree of risk. Your surgical team will help you to understand risk prior to committing to any course of action.

Reasons for and against reconstructive surgery

There are many reasons why children and parents may want to consider having surgery to construct a new ear (or ears). Some are motivated by practical or 'lifestyle' factors such as wanting to be able to wear glasses or earrings, or to tuck their hair behind their ears. Some are concerned about the impact that looking different can have on self-esteem or they want to avoid potential bullying during school. Some are looking to have ears that look like other people's, or that match. Surgery may help to address such issues, but this cannot be guaranteed. Promoting self-acceptance and resilience in your child is important to help your child thrive and you may also want to look into ways to do this instead of, or in addition to, surgery.

Children and adults have varying attitudes regarding surgery. Some are content with their appearance whilst others think that changing how they look would be beneficial. It is natural to be concerned about invasive surgery and the associated downtime from school or holidays. It is also natural to have worries about how the ear may look and feel after surgery. Research evidence suggests that many adults and older children are very happy with the results of reconstructive surgery, but there is always the possibility that you and your child's expectations may not be met.

How do I make a decision with my child?

Reconstructive procedures are invasive, and it is normal to have anxieties about the responsibility of allowing your child to undergo surgery and to wonder whether it is the right decision for them. Therefore, it is important to have an open and honest dialogue with your child in an age-appropriate way regarding the options available, and to try to understand how they feel about surgery. It can be helpful to take the child's lead about when to have these conversations so that they feel comfortable talking and thinking about these issues. Find out what they already know, so you can help them with their understanding and correct any misconceptions about the procedure itself or reasons for having reconstructive surgery.

After understanding the options available, the decision of whether to pursue surgery is a personal one. There are no right or wrong choices and it is important that you do not feel pressured by other people to make any particular decision. If your child wishes to consider surgery, it is important that you have both carefully considered and understood all the information available to you and considered all the positives and negatives of the procedure, in the short- and long-term. If you have any concerns or worries, it can be helpful to speak to your surgical team or other professionals with expertise in psychology and child development. It is important that any decision is ultimately made by you and your child, with support from others who are best placed to support and advise you. The professionals involved should endeavour to remain neutral in that decision making process.

Some parents, and their children, have found speaking to other children, their parents, and adults with microtia about their experiences invaluable. Consider speaking to both those that have and have not had surgery in order to get a balanced view. You can connect with other parents through the Microtia Mingle UK Facebook page and by attending the Microtia UK family days.

It is possible that your own feelings or wishes may differ to those of your child (or other family members). Parents who have previously been in this situation have told us that talking to a psychologist allowed them and their child to think through their options and their motivations for surgery. This helped the parents feel more reassured, especially if their child proceeded with surgery. If you are concerned, there may be a psychologist within your child's surgical team who can help you. If not, your surgeon can refer you to your local paediatric psychology team.

Advice from other parents

The Centre for Appearance Research interviewed ten parents about their experiences of making a decision about surgery. Here is the advice they would give to other parents:

- Consider when to introduce the possibility of reconstructive surgery and prosthetic options to your child.

- Involve your child in decision-making conversations as much as possible.

- Realise that some children do not want surgery and can lead confident and happy lives without it.

- Prepare your child for hospital appointments to discuss surgery. Explain there will be a lot of information to take in, and that they do not have to make an instant decision. You could help them to write down questions they want to ask before attending and take that list into the consultation with them. Reassure them that there are no 'silly' questions and that if something is on their mind or worrying them, then they should tell you and the surgical team about it.

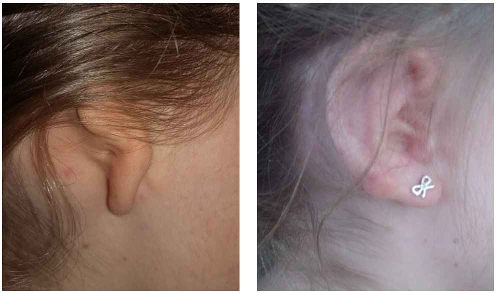
- Realise that surgery alone may not resolve issues such as low self-esteem or bullying.

- Speak to other parents, children and adults who have been through the same process.

- If you are worried your child does not fully understand the procedure, or is not totally sure about their decision, ask to discuss this further with the surgeon and wider team. Speak to the surgeon, anaesthetist and ward staff about pain and pain management before and after surgery.

- Be aware there may be financial implications for some of these options. Whilst the procedure itself is free in the UK, you might need to take time off work, or pay for food, travel, or accommodation if you need to stay away from home. Bear in mind that if a complication were to occur, this might lead to further burden.

- Take time to make the decision and remember that if your child decides not to have surgery at this point in time, they can still discuss their options at a later date and have surgery when they are an adult.



Before and after Rib Cartilage Reconstruction

Further support, and resources:

- **Microtia UK**
  www.microtiauk.org

- **What? Why? Children in Hospital?** produce videos to help children and families prepare for hospital.
  www.wwcih.org.uk

- **Changing Faces** have self-help resources on their website about how to support your child in dealing with the issues they may face and it offers valuable ways to advise and prepare them for situations they may face in the future.
  www.changingfaces.org.uk

- **National Deaf Children's Society** have information and resources on microtia and atresia in children, including how deafness can be managed.
  www.ndcs.org.uk

Microtia UK (Registered Charity No. 1158688) received funding together with the Centre for Appearance Research from the VTCT Foundation for this project.

Reconstructive Surgery for Microtia: Your Child and You
Version 5. 17 June 2020