Prosthetics

- Basic information

In MACS terms a prosthetic refers to an eye. While the idea can be daunting at first they are not just used for cosmetic reasons but also to keep the shape of the eye socket, especially during growth.

What to Expect: Prosthetics, Appointments, and Support

Getting an Appointment
When your child is diagnosed with a MACS condition, your medical team may recommend aesthetic options such as prosthetics. These will not cure the condition but may help with facial symmetry. A specialist consultant will assess whether this option suits your child.

Some hospitals have prosthetics departments, and you'll likely be referred there. However, it's okay to ask about wait times or explore other options if necessary. Moorfields Eye Hospital in London, for example, has expert clinicians and prosthetic teams. You have the right to choose where you receive care.

If your medical team doesn't mention prosthetics, they may lack experience in this area. You can raise the topic, ask for research, or seek a second opinion. Advocacy is key—don't hesitate to ask questions and pursue the best care for your child.

The Psychological Impact
Remember, choosing prosthetics is a personal decision. It's not essential for your child's health, and you cannot be forced into it. Take the time to research, listen to others' experiences, and trust your instincts.
Many parents view this choice as keeping options open for their child's future. While the decision may feel heavy now, it's important to know you're doing your best for your child—and that's enough.

National Eye Service - NAES Patient Journey

1. **Referral and Registration**
   After receiving a referral from a medical professional, your case will be registered with the NAES. You will be contacted by telephone to schedule your first appointment, typically within six weeks.
2. **First Appointment**
   The initial appointment lasts approximately 90 minutes. During this visit, you may receive a temporary half-sphere prosthetic closely matching your existing eye.

3. **Molding Appointment**
   Approximately eight weeks after your case is registered, you will have a two-hour molding appointment. During this session, a socket impression will be taken, and high-quality digital images of your iris and sclera will be captured for colour matching.
4. **Fitting Appointment**
   About six weeks after the molding, you will attend a 30-minute fitting appointment. Guidance on aftercare will be provided during this session.
5. **Check-Up Appointments**
   You will be recalled for a 15-minute check-up 12 months after your prosthetic is fitted.

Contacting NAES
For any inquiries or concerns, you can reach the NAES team by telephone or email.

Manufacturing Process
The National Eye Service combines over a century of traditional craftsmanship with cutting-edge digital and printing technologies, ensuring the highest standards for patients.
At the clinic, a custom lens attachment is used to photograph the patient's iris. This specialized lens removes yellow striations, creating a colour-accurate digital image (CADI) of the iris for precise replication.

The photograph and a wax pattern of the patient's socket are sent to the NAES laboratory, located at the head office in Blackpool, Lancashire.
Traditionally, these patterns guide technicians in hand-painting the iris and determining the veining and staining details required for the prosthetic. Using the patterns, the technician carefully mixes the precise shade for the sclera (the white part of the eye) to achieve a lifelike appearance.

These skills remain a vital part of the service and will be applied as needed during the appointment.
The photograph taken during the appointment is securely uploaded to our server, where our Ocular Technicians use it to hand-paint the iris and create a bespoke artificial eye or cosmetic shell, ensuring a unique fit for each patient.

Once the artificial eye is manufactured, it is polished and thoroughly inspected before being returned to the clinic for the patient's fitting appointment.

Information from NAES July 2024
https://www.naes.nhs.uk/what-we-do/current-processes
https://www.naes.nhs.uk/what-we-do/current-processes/manufacturing-process

- How to clean your prosthetic

Your specialist will advise you on how often you need to visit for prosthetic monitoring. Many individuals have an annual appointment, often affectionately called their "eye polishing day." For some, this becomes a special occasion to celebrate—an "eyeiversary"!

At-Home Cleaning Steps

1. **Nightly Removal:** Unless instructed otherwise by your specialist, you don't need to remove your prosthesis every night.
2. **Cleaning Process:**
    a. Wash your hands thoroughly.
    b. Clean your prosthesis gently using your fingers with warm running water and a mild, unscented liquid soap, washing-up liquid, or simple soap.
    c. Rinse it thoroughly to ensure no soap residue remains.
3. **Important Tips:**
    a. Avoid using detergents, alcohol wipes, disinfectants, or contact lens cleaning products, as these can damage the prosthesis.
    b. Handle carefully to prevent dropping or chipping it.
4. **Storage:** Keep the prosthesis in a clean, small, dry container when not in use.
5. **Professional Care:** Your prosthesis will need occasional polishing and can be resurfaced to maintain its condition.

Guidance for Inserting and Removing Your Prosthesis

Your ocularist will demonstrate how to insert and remove your prosthesis. These instructions are a reference to ensure you can do so correctly.

Inserting Your Prosthesis

These steps apply to all types of prostheses. Most are marked or shaped to indicate the correct orientation:

- **Conformer shells**: Pear-shaped, with the narrow end pointing toward the nose.
- **Temporary artificial eyes**: Have a black spot on the top edge.
- **Artificial eyes and cosmetic shells**: Have four coloured spots along the top edge

Steps to Insert

1 **Clean your hands** and wash the prosthesis with warm water and liquid soap. Rinse thoroughly.
2 **Position the prosthesis**:
    a. Hold it between the thumb and middle finger of your dominant hand.
    b. Place your index finger on the centre, ensuring the dots are visible.
3 **Lift the upper lid**: Use the index finger of your other hand to gently pull the upper lid upward.
4 **Insert the prosthesis**:
    a. Look down and slide the dotted edge under the upper lid.
    b. Once halfway in, release the top lid but keep holding the prosthesis.
5 **Secure the position**:

a. Look up and pull the lower lid down.
b. Push the prosthesis slightly upward until it slips into place.

6 **Adjust if necessary**: If uncomfortable, check alignment in the mirror. Rotate it gently if needed.

Removing Your Prosthesis

There are three primary methods. Your ocularist will advise on the best option for you.

1. Using a Silicone Extractor

1 Wash your hands.
2 Clean and moisten the extractor's cup end.
3 Press the cup onto the prosthesis centre until it adheres.
4 Lift the prosthesis edge from behind the lower lid, pull the extractor forward, and tilt downward
5 Detach the prosthesis from the extractor, wash both, and store them securely.

2. Manual Removal of an Artificial Eye

1 Wash your hands.
2 Avoid looking in a mirror. Look up and gently push the lower lid down until the prosthesis edge emerges.
3 Look down and allow the prosthesis to slide onto your index finger. Catch it with your other hand.
4 Wash the prosthesis and store it safely.

3. Removing a Cosmetic Shell

1 Wash your hands.
2 Place your index finger along the upper eyelash.
3 Look down and push the upper lid upward to the shell's top edge.
4 Pull the eyelash toward your ear to release the shell. Catch it with your other hand.
5 Clean and store the shell.

Additional Notes

For further details, visit Moorfields NHS: Artificial Eye Creation and Fitting.

Things to consider (timing) **Benefits of shells and prosthetics**

Currently, there isn't a treatment for MACS that can restore normal vision. Instead, care focuses on improving facial appearance, making the most of any remaining vision, and supporting the child's overall wellbeing. This often involves working with a team of specialists from different fields. Whether or not to go ahead with recommended treatments is a personal choice and should be based on what feels right for you and your family.

Changing Facial Appearance:
For children with anophthalmia or microphthalmia, early and gradual expansion of the eye socket during the first year of life is usually recommended. This is because the eye socket and eyelids will grow the most during the first three years, with the fastest growth happening in the first year.

If expansion begins early, small expanders can be used. These absorb water and gradually grow on their own, though they may need to be replaced with larger ones over time. Some specialist centers opt to use shells or prosthetics instead and can still achieve great cosmetic results. However, this approach might mean more frequent visits to the prosthetics team in that first year.

After a child turns one, an impression of the eye socket can be made using a special material—similar to the kind dentists use for teeth impressions. This process, called moulding, isn't painful. The prosthetics team can use anesthetic drops if needed to make the process more comfortable.

Using the mold, a custom-made prosthesis (painted or clear) is created. During the fitting, the prosthesis can be adjusted to ensure it fits well, feels comfortable, and stays secure.

The prosthesis or shell helps make the eyes look more alike and can also support the growth of the eye socket. A painted prosthesis is usually matched to the appearance of the other eye, or if both eyes need prostheses, they may be matched to a family member's eye color. During the first three to four years of life, children will need new prostheses more often, but as they grow, these replacements become less frequent.

For example, a patient with no eyeball in the left socket (anophthalmia) may be fitted with a custom-made prosthesis painted to closely resemble their natural right eye.
Credit: Miss Sri Gore, Consultant Ophthalmologist, Moorfields Eye Hospital (London)

Caring for the Prosthesis:
The prosthetics team provides families with important instructions on how to care for the prosthesis, including removing, cleaning, and replacing it. They're also there to help troubleshoot any common problems. Occasionally, other specialists may step in to treat issues like socket irritation or infection.

It's normal for a little sticky discharge to come from the socket, but if the amount increases, it may need medical treatment like eye drops. Sometimes, excessive discharge is a sign that the prosthesis needs replacing. Clues like the prosthesis "spinning" in the socket help doctors and prosthetists make these decisions.

In most cases, the prosthesis is enough to encourage proper eye socket growth and create symmetry between the eyes. However, some patients may need surgery on the socket to make the prosthesis fit more comfortably and securely. These surgeries are tailored to the individual and may involve grafting tissue from other parts of the body, such as fat from the buttocks or lining from the mouth.

Sometimes artificial implants are placed in the socket to help boost its size and support the prosthesis. A small number of children may also need eyelid surgery later in life, often in their early teens, to improve the fit and appearance of the prosthesis further.

Cysts in the Socket:
Some children with microphthalmia or anophthalmia may have a cyst in the socket. These cysts can sometimes only be seen on scans, while others may be visible in the eyelid or socket. Most of the time, cysts don't need to be removed unless they're causing problems. In fact, they can often help the socket grow. If removal is necessary, this is done through surgery.

Maximising Remaining Vision:
For children whose affected eye has some visual potential (like in microphthalmia or coloboma), several strategies can help encourage the best possible visual development.

- Member stories

Making Prosthetics Part of Your Journey

We understand that the decision to use a prosthetic for your child can feel overwhelming. To help you navigate this path, we've included stories and advice from MACS members who have walked this road. These insights may show you how prosthetics can evolve from a source of anxiety into something meaningful—like your child's new party trick!

Member Stories

"Cold Weather and Prosthetics"
"The cold weather affects my prosthetic eye, making the shell cold, which always increases discharge. If I've been outside too long, I sometimes get headaches from the cold hitting the prosthetic shell."

"Learning to Manage the Emotional Journey"
"My husband and I struggled a lot with putting our daughter's prosthetic in at first. It took weeks to get through it without feeling immense guilt over whether we were doing the right thing, especially when it seemed so uncomfortable for her. Please be kind to yourself. Keep learning, researching, and reminding yourself why you've chosen this path, especially during tough times.
We found little tricks that helped—like using a high chair when inserting the prosthetic. Recently, I've even started singing while breastfeeding as I put it in. It's become a part of our life, and it gets easier."

"Understanding the Choice"
"My sister has bilateral anophthalmia (b/a) and chose not to use prosthetics, so when my son was born with b/a, I was shocked at how much pressure medical professionals put on us to use them. In many cases, especially with b/a, prosthetics are purely

cosmetic. It's important for parents to know that it's okay to say no if it doesn't feel right. Your child's face will grow just fine without them.

I've seen upsetting situations where children undergo unnecessary surgeries for cosmetic purposes. Every case is unique, and it's essential to make informed decisions based on your child's needs, not external pressures. This is my experience with bilateral anophthalmia; the decision may be different for other conditions."

Some MACS members have expressed feelings of guilt when making this decision for their child. These feelings often stem from various thoughts, such as concern about trying to "change" their child, even though no parent wishes to alter who their child is. These emotions are entirely normal. This is a nuanced and emotionally charged situation, and it's natural to experience a wide range of feelings, which may evolve over time.

For those who have chosen a prosthetic for their child, reasons often include giving their child options regarding their appearance as they grow, promoting facial symmetry, reducing stares from strangers, and minimising the risk of staring or bullying at school. There are many other personal reasons as well. Remember, your decision is yours alone, and you don't need to explain or justify it to anyone.

MACS members have also highlighted the importance of building their child's confidence in their appearance, both with and without the prosthetic. For many, fostering a positive sense of body image is just as significant as providing the option of an appearance-altering solution.
When it comes to the fitting process, rest assured that it isn't painful for your child. While they may cry initially due to discomfort and the unfamiliarity of the experience, they'll adapt quickly and return to their usual selves soon after. The process can be emotionally overwhelming for parents too, and it's perfectly okay to feel emotional or shed tears. Over time, it does get easier.
Ultimately, you are making this decision because you are a loving and caring parent who wants the best for your child.

At MACS, we're here to support you and your family every step of the way. Together, we can build a stronger, more connected community where everyone has the opportunity to thrive. If you're finding the journey challenging, please don't hesitate to reach out to us at enquiries@macs.org.uk, or connect with others in our Facebook support group. You're never alone – we're here to help.