

Paediatric information

Microphthalmia/anophthalmia

The medical terms are: microphthalmia (pronounced *my-krop-thal-mee-ah*) which means 'small eye'. Anophthalmia (pronounced *ann-opff-thal-mee-ah*) means "no eye". Microphthalmia and anophthalmia is where one or both of your eyes didn't grow properly when your mother was pregnant with you. Sometimes no eye grows at all (anophthalmia) or an eye may not grow to its full size and will be smaller than normal (microphthalmia).

How you see the world

If only one of your eyes has microphthalmia or anophthalmia and your other eye is normal then you will see everything normally, apart from not having true 3D vision (depth perception). If both your eyes have the condition you may only be able to see bright lights and large shapes or you may not be able to see anything at all.

How the world sees you

Your affected eye or eyes will look smaller than normal. The front of your eye may look cloudy or completely white, or your pupil might look a funny shape. If you have no eye then it will look as if your eyelids are closed. Children may be given an artificial

(fake) eye called a prosthesis which looks like a normal eye.

Why did I get this condition?

Most cases happen by chance and the cause isn't always known. Sometimes it is caused by changes in your genes which means your eye didn't form properly. Occasionally, other parts of your face and mouth might not have grown correctly too - e.g. if you have a cleft palate.

How can the doctors tell?

The doctor can tell by examining your eye with special lights and often with an ultrasound scan to look at the size of your eye.

Getting it sorted

Children with anophthalmia or microphthalmia should come to the eye clinic as soon as possible after the eye problem is noticed. You may need several types of tests including:

- ultrasound scan to look at the size of the eye.



- electrodiagnostic tests to check whether the eye can see.
- MRI or CT scan to look at the structure of the eye and brain.
- a blood test to see whether the anophthalmia or microphthalmia was caused by a change in your genes.

You may then be fitted (moulded) with an acrylic plastic artificial eye (prosthesis) to wear on top of your affected eye to make it look like a normal eye and to help your face grow normally. This will have to be remoulded every few months as you grow.

Moulding involves taking an impression of the affected eye or eyes with a special substance called alginate cream, which looks a bit like custard. A wax shape can then be produced from the impression and fitted in your socket to make sure it is comfortable and fits correctly. An iris is painted to match your eye and fixed in the wax shape in the correct position. This shape then has to be made into an acrylic plastic copy and when this is ready you will come back to get your new prosthesis.

Very occasionally, you may need to have an operation on your eye to help the artificial eye fit.

Facts

- Anophthalmia affects 1 in 100,000 babies.
- Microphthalmia affects 1 in 10,000 babies.
- About 30 children are born in England and Wales every year with microphthalmia or anophthalmia.

Further information:

These are patient support groups available for families with your condition:

Micro & Anophthalmic Children's Society (MACS)

22 Lower Park Street

Holyhead

Isle of Anglesey

North Wales

LL65 1DU

Phone: 0800 169 8088

Email: enquiries@macs.org.uk

Website: <http://www.macs.org.uk/>

International Children's Anophthalmia Network (ICAN)

c/o Center for Developmental Medicine and Genetics

5501 Old York Road

Genetics, Levy 2 West Philadelphia, PA 19141

Phone: 1-800-580-ican

Email: ican@anophthalmia.org

Website: <http://www.anophthalmia.org/>





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more information about your rights
under the NHS constitution, visit
www.nhs.uk/choiceinthenhs

**Moorfields Eye Hospital NHS
Foundation Trust**
City Road, London EC1V 2PD
Phone: 020 7253 3411
www.moorfields.nhs.uk

Moorfields Direct telephone helpline

Phone: 020 7566 2345
Monday-Friday, 8.30am-9pm
Saturday, 9am-5pm
Information and advice on eye
conditions and treatments from
experienced ophthalmic-trained nurses.

Patient advice and liaison service (PALS)

Phone: 020 7566 2324/ 020 7566 2325
Email: moorfields.pals@nhs.net
Moorfields' PALS team provides
confidential advice and support to help
you with any concerns you may have
about the care we provide, guiding you
through the different services available
at Moorfields. The PALS team can also
advise you on how to make a complaint.

Your right to treatment within 18 weeks

Under the NHS constitution, all patients
have the right to begin consultant-led
treatment within 18 weeks of being
referred by their GP. Moorfields is
committed to fulfilling this right, but if
you feel that we have failed to do so,
please contact our patient advice and
liaison service (PALS) who will be able
to advise you further (see above). For

