



Patient information: ocular oncology service

Removal of an eye

This leaflet is for patients who are to undergo an operation to remove the eye, called enucleation.

When you were told that you need an eye removed, naturally you may have been shocked and afraid about what the operation involves and about your appearance after the operation. This is a normal reaction and we hope this leaflet can address some of the anxieties and answer some of the questions that many patients may have.

We also have a 'single eye vision' leaflet written by one of our patients, which you may find helpful for practical and emotional advice on coping with daily life following your enucleation. You may also find our 'care of your prosthetic eye' leaflet useful guidance ahead of having your artificial eye fitted. Please ask a member of staff for a copy of these leaflets or visit our website to download them: www.moorfields.nhs.uk

Frequently asked questions:

Why do I need an enucleation?

This operation is sometimes necessary to treat eye cancer. It is only undertaken if all other treatment options are ineffective. Your doctor will have discussed the treatment options with

you and explained that this is the best treatment for you. The aim of the operation is to remove your tumour.

What does enucleation involve?

An enucleation operation is where the eyeball is removed. The eyelids, eyelashes, eyebrows and surrounding skin will be left as they are. The eyeball is set inside the protective bony eye socket (orbit). The eyelids protect the front of the eye and are lined with a protective membrane called the conjunctiva, which also covers the front of the eyeball. The optic nerve is attached to the back of the eyeball. There are muscles attached to the surface of the eyeball which are responsible for moving the eye.

During the operation, the optic nerve and eye muscles are cut and the eyeball is carefully removed. It is replaced with an orbital implant in the shape of a ball. Some of your eye muscles are then stitched to the orbital implant so the eye muscles will be able to move the implant. This means that when your artificial eye is fitted at a later date it should move in a similar way to your normal eye. At the end of the operation, your conjunctiva the membrane lining the

eyelids), is positioned so that it covers the implant, giving the eye socket a pink appearance. After surgery, a temporary transparent plastic shell is put in place in the eye socket, to allow healing and give shape.

After approximately eight weeks, the clear shell will be replaced by an artificial eye (prosthesis). The prosthesis is shaped like a large contact lens and will sit in your eye socket over the orbital implant. You will be shown how to remove it so that you can clean it when required. More detail can be found in our 'care of your prosthetic eye' leaflet, please ask a member of staff if you would like a copy or visit our website to download it: www.moorfields.nhs.uk.

Are there complications with an enucleation operation?

The operation is usually straightforward but as with all surgery there is a small risk of complications. Short-term complications can include bleeding, swelling and infection. Long-term complications can include discharge and socket irritation or exposure of the ball implant.

Where will I have the operation?

Your operation will take place at Moorfields City Road or St Bartholomew's Hospital; you may need to stay in for one night. Please ask the clinical nurse specialists or preassessment nurses to arrange this for you if you would prefer this.

What happens before the operation?

You will be seen by one of the doctors and an anaesthetist, and you will be asked to sign a consent form for the operation which is performed under general anaesthetic.

The eye that is to be removed will be carefully marked and checked again just before the operation.

How long does the operation take? The operation lasts about one hour.

What will happen after the operation?

You will go back to the ward after surgery with a firm dressing in place to help reduce swelling. This will stay in place for about one day. Your eye may feel a little painful and sore, and you will be given pain killers if you need them. The day after the operation the dressing will need to be removed. Your eye socket will look red but it will become pinker in colour as it heals. Some bruising and swelling of the eyelids may occur; this can become worse over the first few days before gradually getting better.

You will be able to see the clear plastic shell that has been placed in your eye socket. This has a hole in the middle to help with airflow and drainage. It is easily removed but should stay in place until your socket heals and a temporary artificial eye is able to be fitted. The nursing staff will show you how to clean your eye socket and give you some information on taking care of your eye and the shell. When you go home it is best to keep your eye uncovered to



help healing but you can wear dark glasses until the swelling goes down. Very occasionally the shell may fall out. This rarely happens but if it does, please ensure you follow the cleaning and care instructions the nursing staff give you after the operation.

Will I need aftercare medication?

You will be asked to put in eye drops for one month to prevent infection and take oral antibiotics for one week. Paracetamol can be taken if required for pain relief.

How may I feel after the operation?

You may feel upset after having your eye removed, especially if you had some sight in your eye before the operation. Your emotions may fluctuate as you realise you are losing, or have lost, a part of you. You may also feel grief, sadness, bitterness and anger, and initially find it difficult to come to terms with having only one eye. Some patients have the sensation that the eye is still there or have temporary visual hallucinations or flashing lights. This is all quite normal and will improve over time.

If you would like to talk to someone about coping after having an enucleation you can arrange to see one of our nurse counsellors or talk to one of our ocular oncology clinical nurse specialists. You can also contact one of several helpful organisations (Contact details are at the end of this leaflet).

When will I have my follow up appointment?

Once you have been discharged you will be sent an appointment to come back to the clinic for a follow up in about a month. You will also need another appointment approximately three months after the first appointment. You may also need additional radiotherapy to complete the treatment of your eye but this will be discussed with you when you attend your first follow up appointment after the operation.

When do I get my artificial eye?

Once your socket has healed, your ophthalmologist will refer you to the ocular prosthetics department for measurement and fitting of a temporary artificial eye, taken from stock to replace the shell. This will be similar to your eye but not an exact match. Your final artificial eye will be made for you and custom painted to match your other eye. This will involve taking a mould of your eye socket so that it is the exact shape of your eye socket and fits over the orbital implant. This is a painless procedure that can take up to two hours, but ensures the eye's shape, size and colour is made to match your own.

The process of making a prosthesis takes about a month and you will be fitted with a temporary prosthesis until your permanent one is ready. More detail of what to expect can be found in our 'care of your prosthetic eye' leaflet, please ask a member of staff if you would like a copy or visit our website to download it: www.moorfields.nhs.uk.



Once fitted, your artificial eye should have an adequate range of eye movement. You will be able to sleep with it in place and once the socket is completely healed you can continue with your life as usual. Eye make-up can be worn and you can swim or do other water sports (you are advised to wear goggles to avoid loss of the artificial eye). You are also advised to wear eye protection when doing any activity that could potentially cause injury to the other eye (e.g. DIY).

Can I drive after having my eye removed?

You can drive a car as long as the vision in your normal eye meets the legal requirements for driving and you have an adequate field of vision. You will need to remember that your overall vision will be reduced and you will have to turn your head more frequently while driving to compensate for the lack of vision on one side, however you will adapt to this over time. You will also need to take extra care when driving at night. Please note that you will no longer be allowed to drive cabs, lorries or buses.

Advice and support available at Moorfields:

Ocular oncology nurse specialists

Our ocular oncology nurse specialists are based in the ocular oncology clinics at Moorfields Eye Hospital at City Road on Tuesdays, Thursdays and Fridays. They will be able to answer any queries you may have about your treatment.

Contact details:

- Sinead Hanrahan
 Phone: 0771 1765 371during office hours
- Nana Gyasi-Twum
 Phone: 0788 5447 138
 during office hours.

Moorfields ocular oncology secretaries:

- 020 7253 3411 ext. 4872 / 2267
- 020 3465 5513

Moorfields ocular oncology appointments:

- New appointments: 020 7521 4648
- Follow-up appointments:020 7566 2357, choose option 3 for oncology.

Nurse counsellors

If you are finding it difficult to come to terms with your diagnosis and the treatment that you require, you may find it helpful to speak to one of our nurse counsellors based at Moorfields City Road. Counselling provides an opportunity to talk things through, allowing you the time to explore your thoughts and feelings and to make sense of the way you feel. The counsellors are based in City Road and are able to offer confidential, face-to-face counselling to all adult patients over the age of 18yrs. The service is available Monday to Friday 9-5pm.



Contact details:

Email:moorfields.referralscounselling@

nhs.net

Phone: 020 7566 2385.

You may need to leave a voicemail but please do not worry as this line is confidential. It is helpful to keep the message short and clear, including your contact details.

Your clinician can also refer you to the counselling service. If we are not able to help, we will be able to talk things through with you or point you in the direction of alternative support.

Eye clinic liaison officers (ECLOs) -

Eye clinic liaison officers (ECLOs) are available at Moorfields Eye Hospital in City Road to assist those living with sight loss. This includes patients, their relatives and carers. For more information about ECLO services at City Road, please ask a member of staff for an information leaflet, these are also available at the health hub, located at the main entrance of the hospital. Phone: 020 7566 2355 or email: moorfields.cityroadECLO@nhs.net

In need of urgent help?

If you are feeling very distressed, despairing or suicidal and need immediate help, please contact your GP and ask for an emergency appointment. If your GP is closed, please consider calling the national non-emergency number 111.

You can also go to your nearest Accident and Emergency (A&E) department where a mental health practitioner will be able to assess you and give you appropriate help.

Other sources of support available:

Macmillan Cancer Support

www.macmillan.org.uk
Tel: 0808 808 00 00
Macmillan provide practical, medical
and financial support and advice for
people going through cancer.

Changing Faces

www.changingfaces.org.uk General enquiries tel: 0845 4500 275 Support service helpline: 0300 012 0275

A charity for people and their families who are living with conditions, marks or scars that affect their appearance.

Maggies Cancer Support Service St Bartholomew's Hospital London www.maggiescentres.org

Certificate of Visual Impairment (CVI) Information about sight loss and

registration.

Phone: 0207 566 2355

Mental health support -Samaritans

A free 24 hour helpline for anyone in mental distress.

Phone: 116 123 or email:

jo@samaritans.org

Website: www.samaritans.org

MIND

Provides mental health information, advice, counselling and advocacy. Phone:0300 123 3393 or email: info@mind.org.uk



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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