



Patient information: ocular oncology service

Going home after enucleation (removal of an eye)



This information leaflet should provide answers to any questions you might have after your operation to remove an eye.

Immediate post-operative care

- You will be sent home with an eye pad. Make sure you remove this when you get home or the next day because the fresh air reduces the risk of infection in the socket.
- Wipe away any mucus or blood with cotton buds dipped in boiled water that has been allowed to cool down. Do not touch the socket itself.
- Administer your antibiotics as prescribed, to prevent infection.
- Be sure to wash your hands before and after instilling any drops or ointment. You do not need to remove the conformer to instil the antibiotics.
- If you feel excessive discomfort, this can be alleviated with paracetamol.
- You can shower, take a bath and wash your hair as soon as you wish, but take care not to let water get into your eyes. Your ophthalmologist will advise you when you can resume driving,

swimming and other activities. When swimming or diving, you should wear goggles over the prosthesis.

What to expect

-There may be **swelling and bruising** of the eyelids, which can increase in the first few days after your operation, but this should improve over a week or two.

-Do not worry if you appear to be seeing **colours and other images** through the eye that has been removed. This is called '**phantom eye**' symptom and stops after a few days or weeks.

-After a few days, your eyelids will begin to open, to reveal the **conformer**, which is a rigid, transparent, plastic, cup-shaped 'contact lens' with a hole at its centre. The conformer is designed to prevent the socket from shrinking.

- A nurse will show you how to look after your conformer. It is helpful for you to have someone with you when this is done, in case you need help when you are home. You will need to **keep your conformer clean** by rinsing it in soapy water that has been boiled and allowed to cool down.

-If the conformer **slips out of the socket**, please replace it as soon as you can. Wash your hands and rinse the conformer in lukewarm water that has been boiled for a few minutes (the conformer should not be exposed to heat).

-To **insert the conformer**, hold it at its lower edge with the fingertips of your right hand and push it upwards under the upper eyelid as far as you can. Then, while keeping it in place with a finger of the left hand, drag your lower lid down with a finger of your right hand so that the lid margin flips over the edge of the conformer.

-If you are not able to **replace the conformer** on your own, please phone the ward or the ocular oncology clinical nurse specialist for advice during office hours. If you do not feel able to cope, arrangements can be made for a **district nurse to visit you at home**.

-Before you receive your artificial eye, you may want to wear dark glasses. Once you start wearing your prosthesis, you will find that others do not notice that you have lost an eye or are not bothered by your appearance.

This information can be made available in alternative formats, such as easy read or large print on request. Please call PALS: 020 7566 2324/ 020 7566 2325





Artificial eye clinic

You will be given an appointment to see the prosthetist **after about six weeks**, where a mould will be taken of your socket so that a prosthesis (artificial eye) of the right size, shape and colour can be prepared. This procedure is relatively painless - the prosthetist might use some anaesthetic drops if needed. A temporary artificial eye will be fitted, which will match the other eye as closely as possible. A few weeks later, you will attend the artificial eye clinic a second time to receive your permanent prosthesis.

You will be able to open and close your eye over the prosthesis, which will move with the other eye. You should wear your prosthesis when you sleep. Tips on **managing your artificial eye** as well as information leaflets will be provided by your prosthetist.

Please make sure **not to miss your appointments** at the artificial eye clinic. If, for any reason you cannot attend your consultation, please inform the clinic as soon as you can. This way, your slot can be given to another patient and alternative arrangements can be made for you to receive your care in a timely manner. Please keep the **contact details of your prosthetist** handy – this is in case any problems arise and because you will be reviewed at regular intervals for inspection and polishing of the artificial eye.

Coping with loss of vision

Loss of vision from one eye restricts your **field of vision** on that side. Because of the limited field of vision, you may bump into things or people on the side of the eye that has been removed. You will need to turn your face towards that side to avoid this problem. Special care must be taken when crossing a street or if you are driving a car or riding on a bicycle or motorcycle.

Removal of an eye also reduces your **depth perception**, especially when you look at things close to you. This means you need to be especially careful when navigating stairs, pavements or uneven ground and when performing tasks such as pouring drinks and placing objects onto a table. These difficulties may be frustrating at first but will lessen over a few weeks as you adjust to seeing with one eye.

Protecting the other eye

A common misconception is that the remaining eye needs to work harder to compensate for the eye that has been removed. As a result, some patients restrict their activities. This is quite unnecessary because the eye is not strained by use.

Special care must be taken to **avoid injury to the remaining eye**. For example, safety glasses must be worn when performing any hazardous activities, such as hammering a nail or using a power tool. A wise safety precaution is to wear glasses with polycarbonate lenses.



Driving

You can **legally drive with one eye**, as long as a car number-plate can be read from the correct distance (20 metres). Please refer to the **DVLA website** for up-to-date regulations. You should inform your car insurance that you have had an eye removed. Your insurance premiums should remain unchanged.

Work

Your ability to **return to work** will depend on your occupation. You can be provided with a return-to-work certificate on the ward or you can get this from your GP.

Long-term follow-up

As soon as possible, you will be discharged from Moorfields to the hospital close to your home, where your team will have all the expertise needed to continue your care. This should reduce your travel costs and risk of coronavirus infection. Your local ophthalmologist will be able to get in touch with us or will refer you back to us if any questions or problems arise.

Potential side effects of enucleation

Problems with socket

You may experience some grittiness. There may also be some mucoid discharge. This is clear and odourless, unlike pus, which is yellow or green. An excessive amount of mucus may occur if the artificial eye is scratched or if it needs polishing by the prosthetist.

Drooping of upper eyelid There may be drooping of the upper eyelid/a groove may develop beneath the eyebrow. These can be reduced by fitting a larger prosthesis or by a surgical operation.

After several years, the weight of the artificial eye can cause the lower eyelid to sag; this is easily treated by a small operation, performed as an outpatient procedure under local anaesthesia.

Ulceration of the conjunctiva

Rarely, the buried ball implant causes ulceration of the conjunctiva. This is treated by surgically removing the implant and replacing it with a new one.

Psychological/emotional difficulties

Although recovery usually occurs within a few days or weeks, a variety of emotions are likely to be experienced in the early days after removal of an eye. Many patients feel a sense of bereavement for the eye that has been lost. This is a natural reaction and not a sign of weakness. Some patients experience anxiety about the tumour behind the artificial eye returning, which is extremely rare. Others have expressed worry that if the eye was removed because of melanoma, other tumours could be developing in the liver and other parts of the body. To help alleviate these worries, please feel free to speak to one of our **ocular oncology clinical nurse specialists**

or ask to be referred to see one of our nurse counsellors (see details opposite and on page 5). There are also other sources of support available within and outside Moorfields, which are outlined in more detail on pages 5- 6.

Please be reassured by in-depth studies which have shown that, once adjustment has occurred, wellbeing after removal of an eye is as good as after ocular radiotherapy and not significantly worse than in the general population. This research has also found that when quality of life is diminished, this is usually because of factors unrelated to the ocular condition. With time and patience, you will overcome any difficulties arising from removal of your eye, especially with support from friends and relatives.

To find out more about this procedure, you can watch our short video by scanning the QR code below:



If you need to change or reschedule your follow-up appointment Please call **020 7566 2357** and choose option 3 for oncology.

For non-medical queries, please contact our ocular oncology medical secretaries

- Pamela Jackson : **020 7253 3411 ext 4872**
- Angela Edgar : **020 7253 3411 ext 2267**

If you have any medical concerns, please contact the ward or the ocular oncology clinical nurse specialists (CNS). Please note that they may be in clinic at the time and so will respond to your query when they can.

- Sinead Hanrahan: **07711 765 371 (Monday-Thursday)**
- Nana Gyasi-Twum: **07885 447 138 (Tuesday, Thursday, Friday)**

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-toface

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 or your local centre can be found at: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.

