

**THE  
LIVERPOOL OCULAR ONCOLOGY CENTRE**

**A guide for patients**

**Bertil Damato**

**6<sup>th</sup> Edition**

# **THE LIVERPOOL OCULAR ONCOLOGY CENTRE**

**A guide for patients**

**Bertil Damato**



**The oncology team**

---

# Contents

## **Part 1: Overview**

Introduction	2
1. The ocular oncology centre	4

## **Part 2: Your care pathway**

2. The referral process	7
3. Your first visit	8
4. Ocular investigations	11
5. Treatment of ocular tumours	15
6. Your hospital admission	20
7. Follow-up	25
8. After your discharge from our centre	27
9. Frequently-asked questions	28

## **Part 3: Behind the scenes**

10. Research	34
11. Audit	38
12. Teaching	40
13. Keeping up to date	44

## **Part 4: Miscellaneous topics**

14. How you can help	46
15. The Patient's Charter	48
16. How to make a complaint	50
17. Who's who	51
18. Directory	55
19. Hospital facilities	56
20. How to get there	57
21. Liverpool and surroundings	62
22. Useful contacts	65
23. Ocular tumours	67
24. Evidence of excellence	71
25. Glossary	72

---

# Introduction



Professor Bertil Damato  
Consultant Ophthalmologist,  
Ocular Oncologist



Mr Carl Groenewald  
Consultant Ophthalmologist,  
Ocular Oncologist and  
Vitreous-Retinal Surgeon



Professor Heinrich Hiemann  
Consultant Ophthalmologist,  
Ocular Oncologist and  
Retinal Specialist

At the Liverpool Ocular Oncology Centre (LOOC), we specialise in the diagnosis and treatment of adult ocular tumours. I must emphasize that the word ‘tumour’ means nothing more than ‘lump’. Although we provide an oncology service, most patients coming to our clinic have a benign tumour, such as a cyst, haemorrhage or naevus (i.e. ‘mole’). The tools and expertise required for diagnosis and treatment of these conditions are similar to those needed for more serious disease. Do not assume that you have a dangerous condition just because you are referred to an oncology centre.

This guide is written for you, our patient, and your relatives and doctors. The objective of this guide is to let you know what to expect when you visit our centre and to help you understand why we do things in a certain way.

Our aim is to empower you to be more active in managing your own care. We would like you to have a good understanding of your condition and its treatment so that you can let us know your needs and concerns. We would also like you to help us improve our care by giving us feedback on how we’re doing and by making suggestions.

This guide inevitably contains a certain amount of jargon. A glossary is therefore printed at the end of this text.

This is the sixth edition of our guide. Information that might worry some patients has been removed and is available separately, upon request. Hopefully, you will find this guide interesting, useful, and not too stressful. Please feel free to keep this guide for future reference.

This guide is funded by the National Specialist Commissioning Team, which sponsors our service. I am grateful to all involved for their assistance.

For further information please visit our website at [www.eyetumour.com](http://www.eyetumour.com)

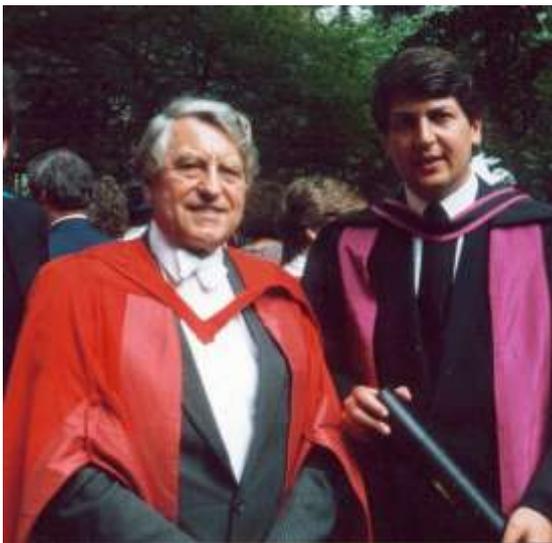
**Professor Bertil Damato PhD FRCOphth,**  
Consultant Ophthalmologist/Ocular Oncologist  
Clinical Lead, Liverpool Ocular Oncology Centre

# Overview

# 1

## The Ocular Oncology Centre

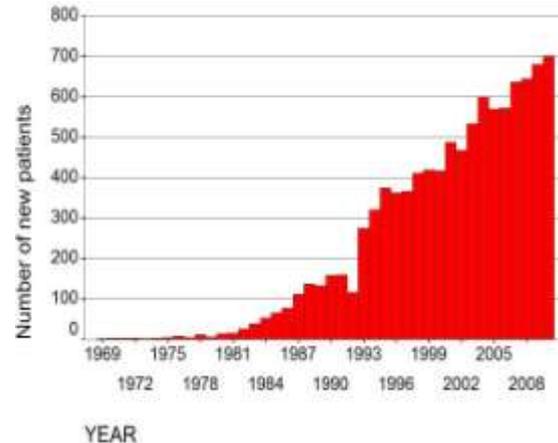
The Ocular Oncology Centre at the Royal Liverpool University Hospital was established by Bertil Damato in January 1993. He became interested in ocular oncology in 1980, when he started working at the Tennent Institute of Ophthalmology in Glasgow under the leadership of Professor Wallace Foulds, whose pioneering surgery for ocular tumours had received world-wide acclaim.



**Professor Wallace S Foulds CBE and Bertil Damato (1987)**

In 1989, Professor Foulds retired and Dr Damato continued to run the oncology service. In 1993, Mr Damato moved to Liverpool, which is more accessible to most patients, being located at the geographic centre of the British Isles. Liverpool is close to the Clatterbridge Centre for Oncology, which is the only unit in Britain with facilities for proton beam radiotherapy of ocular tumours.

The Liverpool Ocular Oncology Centre grew rapidly, with the number of new patients each year now reaching 700.



The Liverpool Ocular Oncology Centre has developed considerably over the years and the team now includes full-time oncology secretaries, specialist ocular oncology nurses, a health psychologist, a data manager, photographers, a research scientist in ocular tumour biology, and a compliance officer. Close collaborative links have been established with retinal specialists, pathologists, cyto-geneticists, radiotherapists, oncologists, radiologists and also a medical ethicist to provide a comprehensive service.

In 1997, the Ocular Oncology Centre was designated a Supra-Regional Service by the National Specialised Commissioning Group (i.e., 'NSCG') in London. The purpose of this organisation is to ensure that patients with rare conditions, such as ocular tumours, are given the highest possible standard of care by an experienced specialist team.

The Liverpool Ocular Oncology Centre offers an exceptionally wide range of treatments, which include:

- Plaque radiotherapy, placing a saucer-shaped applicator behind the eye for 1-7 days;

- Proton beam radiotherapy, using special equipment, located at Clatterbridge Centre for Oncology, on the Wirral Peninsula;
- Trans-scleral local resection, removing the tumour through a trap-door in the wall of the eye;
- Trans-retinal local resection, 'hoovering' the tumour through a hole in the retina;
- Trans-pupillary thermotherapy; sterilizing the tumour with a beam of infra-red laser;
- Photodynamic therapy, injecting a light sensitizer into a vein in the arm and then shining low-energy laser onto the back of the eye to activate the sensitizer as it passes through the tumour,
- Topical chemotherapy, using eyedrops to treat tumours on the surface of the eye, and
- Enucleation, removing the eye, if other methods are unlikely to conserve the eye with useful vision.

These treatments are useful both for benign and malignant tumours. The wide choice of treatment enables us to design the optimal strategy for each patient, if necessary combining different methods to achieve the best possible results.

Special investigations include:

- Colour photography using a range of cameras, for documenting tumour appearances;
- Fluorescein angiography, for investigating tumour circulation;
- Ocular ultrasonography; for measuring tumour dimensions and tissue consistency;
- Optical coherence tomography for assessing the layers of the retina and detecting fluid under the retina;
- Tumour biopsy, performed either using a fine needle, or a 25-gauge

vitreous cutter, ('vacuum cleaner') or through a trapdoor in the eye;

- Computerised tomography, for producing x-ray images of the eye;
- Magnetic resonance imaging, producing fine images of the eye; and
- Cytogenetic studies of melanoma, for detecting DNA abnormalities in the tumour, which give an indication of prognosis.

We have instituted several protocols to help patients understand their condition and its treatment. These include:

- Giving patients a series of guides and information leaflets;
- Giving all new patients a CD-ROM or tape cassette with an audio-recording of their first consultation;
- Mailing patients a copy of the correspondence we send to the GP and ophthalmologist;
- Creating a website; and
- Providing a telephone helpline, run by our Specialist Nurses.

Our clinics include:

- New patient clinics on Mondays;
- Follow-up clinics on Thursdays and on Friday afternoons;
- Conjunctival tumour clinics on Thursday afternoon, once a month
- Nurse Oncology Clinics on Thursday afternoons.

To maintain high standards we also:

- Conduct multidisciplinary team meetings;
- Prepare staff guidelines;
- Conduct patient satisfaction surveys and quality of life studies;
- Measure satisfaction of referring ophthalmologists;
- Conduct research;
- Encourage complaints; and
- Perform continuous outcomes assessments (ie, Audit).

# **Your Care Pathway**

## 2

# The Referral Process

---

You have been referred because your eye specialist has identified a tumour (lump) in or on your eye. In many cases this will be benign but there is a chance that it may be malignant. We aim to see all patients within two weeks of receipt of your referral from your specialist.

Eye specialists refer patients to us by sending a letter or fax or by making a telephone call. As soon as we receive your referral we will send you:

- details of your appointment time and place;
- this guide;
- a questionnaire, to confirm that details regarding your name, date of birth, address and general practitioner are all correct;
- a request for permission to send a copy of a report on your condition to your optometrist (i.e., optician) after your first visit to our centre. It is important to give optometrists this feedback, for educational purposes, but your consent is needed as optometrists are not doctors; and
- a request for permission to use your data and any images for research, teaching and quality control studies.



**The Ocular Oncology Office**

Please return the completed forms to the ocular oncology secretary as soon as you can.

If you live too far from Liverpool to travel on the same day, our secretary will arrange accommodation for you. At present, we pay the hotel for the room (single or double) so you will only need to pay for breakfast and any extras (telephone, parking, etc). The accommodation will either be at a hotel or in an apartment across the street from the hospital.



**Royal Chambers**

The hotel selected is a short taxi ride from the hospital. There are, of course, several other hotels around Liverpool and if you do not mind travelling a greater distance to the hospital or contributing to the cost, if the hotel is more expensive, then our secretary would be happy to find alternative accommodation. If you travel to our centre by car, please aim to arrive early in case you are delayed.

If you have any special requirements please let us know by mail or phone and we will do everything we can to meet your needs.

# 3

---

## Your first visit

### **Registration**

When you arrive at the eye outpatient clinic make your way to the reception desk. You will be asked for your appointment card and registered on the computer system. You also be given a questionnaire about your health.

### **Examination by Nurse**

Once you have registered, you will be asked to take a seat in the waiting area until you are called by the sifting nurse, who will:

- Measure your vision with the letters chart;
- Measure the intraocular pressure (i.e. tonometry);
- Test the pupillary reflexes with a torch;
- Ask about your general health, as well as any medications and allergies; and
- Instill drops into both your eyes to enable examination of each fundus (i.e., back of the eye) by ophthalmoscopy.

These drops will probably blur your vision so that you may be unable to read without appropriate spectacles for up to four hours. Remember also that you should not drive a car until you are once again able to read a number plate from the legal distance.

If your tumour is located on the iris, the pupils will not be dilated until the consultant has examined you.

### **Outpatient Clinic**

The nurse can store your luggage in a cupboard, if you wish. However, the hospital cannot be held responsible for any

loss or theft, so please keep any valuable items with you.

### **Examination by Surgical Trainee or Fellow**

After seeing the sift nurse, you will be seated in the waiting area again until you are called to see the specialist registrar, who will:

- Introduce himself or herself;
- Confirm your name and age;
- Ask you about how and when you first became aware of your ocular condition;
- Ask about the sequence of events leading to your referral to our centre;
- Ask about your general health and previous illnesses;
- Review your health questionnaire with you, if you have already completed it;
- Examine the front of your eyes with a slit-lamp; and
- Examine the back of your eyes with an ophthalmoscope.

We are interested in how your tumour was detected and how your condition was managed prior to your referral to our centre. This is because we are conducting a study into the detection of ocular tumours in the community. We hope this investigation will in future result in earlier diagnosis and treatment.

### **Photography**

After seeing the specialist registrar, you will be asked to wait outside the consulting room until you are called for photography. The photographer will check your name and age before asking you to position yourself at the camera. Please try

to keep your eye wide open while the photographs are being taken.

With your consent, your portrait may be taken. This is only so that we can see this on our computer screen whenever we are speaking to you by telephone.



### **Fundus photography in progress**

Your ocular photographs will be used:

- To compare tumour appearances with any future photographs so as to be able to recognize growth or regression; and
- For teaching in lectures at scientific meetings and publications.

In any publications, your anonymity will be respected. Your permission for publication will be requested using a consent form. A special section of the form will need to be signed if you may be recognised from the photographs.

After the photography you will be asked to sit in the waiting area until you are seen by the consultant ocular oncologist.

### ***Examination by Consultant***

We now have three consultants specialising in ocular oncology and you will be under the care of one of these. The consultant will:

- introduce himself;
- review your referral letter and the case notes;
- examine your eyes;

- perform ultrasonography, which is useful for diagnosis and for measuring tumour size;
- perform wide-angle photography of the back of your eye, if this is likely to be useful;
- explain to you as much as possible about your condition; and
- plan your future care with you.

If any close relatives or friends have come with you to the hospital they are welcome to accompany you during your consultation.



### **Counselling by consultant**

A plastic model eye or 3-D photographs will be used to help you understand the structure of the eye.

You are of course encouraged to ask questions, although these are best left to the end of the examination.

An audio-recording of your consultation will be given to you on CD-ROM or tape cassette to help you remember what was said. Most patients seem to find this very useful and are quite surprised by the amount of information they missed the first time.

### ***Discharge from Clinic***

If on the basis of size and appearance your tumour is considered to be benign and if it does not require treatment, you will be allowed home and discharged from our clinic.

A letter will be written to the consultant ophthalmologist at your home hospital describing the clinical findings, stating the diagnosis and advising on future care.

Copies of the letter will be sent to you, your GP and, with your consent, your optometrist. If there is anything you do not understand please phone our nurse.

If you need to return to our centre, we will give you an appointment sheet. This should be taken to the reception desk, where a specific date for your next appointment will be selected. Our receptionist will give you an appointment card.

### ***Treatment Selection***

If you need treatment, then all the therapeutic options will be discussed, together with treatment schedules, possible side effects, and likely outcomes.

You will be helped to choose the best treatment for your particular condition. If possible, a decision is made by the end of your visit, but you would still be able to change your mind afterwards.

If you are to receive radiotherapy for an intraocular melanoma, the risks and benefits of tumour biopsy will be discussed with you. This involves obtaining a tiny tumour sample just before or after your radiotherapy. Lab tests will show whether or not the tumour is life-threatening.

Your care will be discussed at a multidisciplinary meeting immediately after the clinic. This is attended by doctors, nurses, and administrative staff. It is possible that your treatment plans might be altered following these discussions, in which case we will speak to you about any revisions without delay.

If you need more time to reach a decision, this is quite possible, of course.



**Multidisciplinary meeting**

### ***Counselling by Nurse***

After your consultation you will be taken to a quiet room, where a nurse will go over what was said, answering any more questions that might come to mind. You will receive an information prescription ([www.nhs.uk/ips](http://www.nhs.uk/ips)) specifically tailored for your health condition providing information on a several topics ranging from cancer charities to local information about cancer.

If you would like to speak to another patient who has previously received the same treatment as yourself then the nurse would be able to arrange for you to speak to this volunteer by telephone.

A computerised kiosk in the waiting area is available so that you can find out more about your condition and its treatment.



**Kiosk in waiting area with information for patients and relatives**

# 4

## Ocular investigations

This chapter describes the various examinations and tests that are in common use at our clinic. You may find it useful to refer to the diagram of the eye in the Glossary.

### *Slit-lamp examination*

The slit-lamp allows a highly-magnified view of the eye, with well-controlled illumination providing a clear view of the tumour. The source of light can either be diffuse or slit-like (hence the name of the instrument). It is possible to adjust the length of the slit, which can therefore be used to measure the size of a tumour.

### *Ophthalmoscopy*

The back of the eye is examined with a variety of ophthalmoscopes, which give a stereoscopic and panoramic view of the tumour and its surroundings.



**Binocular indirect ophthalmoscopy**

Most tumours can be diagnosed by their appearance on ophthalmoscopy or slit-lamp examination. It may be necessary to monitor a lesion over several months or years to detect growth, thereby confirming the diagnosis.

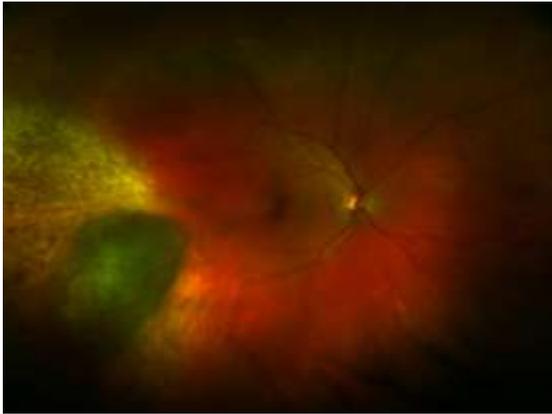
Difficulties can arise if the tumour is not visible because of haemorrhage or cataract. These can be overcome by treating the cataract, waiting for the haemorrhage to clear spontaneously, or perhaps removing the haemorrhage surgically.

### *Colour photography*

Colour photography is useful for documenting the appearances of the tumour so that any change over time is readily detected. Standard cameras can only image tumours extending far back in the eye, near the fovea and optic disc. We now have wide-angle cameras, which can photograph tumours that are beyond the reach of standard cameras. The Panoret camera uses a contact lens whereas the Optos is a non-contact device. Both cameras are sponsored entirely with donations and legacies from our patients.



**Wide-angle photography in progress**

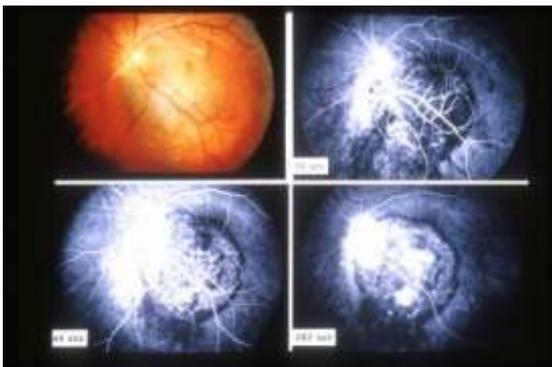


**Optos photograph showing a panoramic view of the back of the right eye. (This shows a choroidal melanoma after successful plaque radiotherapy.) Contrast the wide view with that of the photograph below, taken with a conventional camera.**

### ***Angiography***

Angiography is performed by injecting a dye into a vein in the arm and then taking a series of photographs of the back of the eye.

The dye is fluorescent; that is, it has the property of changing light from one colour to another. The photographs are taken using a flash and a filter of the appropriate colours. The dye can therefore be seen shining brightly as it passes through the arteries and veins and as it leaks through any abnormal areas. There are two kinds of angiography: fluorescein angiography and indocyanine green angiography, which use blue and red light respectively.

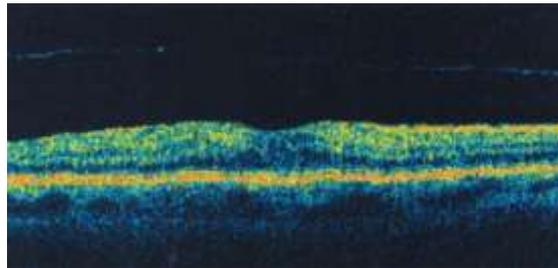


**Fluorescein angiogram**

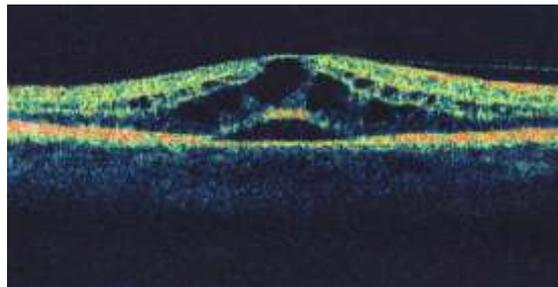
The injected fluorescein dye tends to cause yellowing of the skin and urine for a few hours and about one in ten patients experience transient nausea, although vomiting is rare. About one in 2000 patients develops an allergic reaction, which very rarely is fatal (i.e., in about one in two hundred thousand patients).

### ***Optical Coherence Tomography***

This camera optically produces an image showing a 'slice' of the retina, with the various layers having different colours. It is useful for detecting abnormal fluid at the back of the eye.



**OCT Scan of macula**

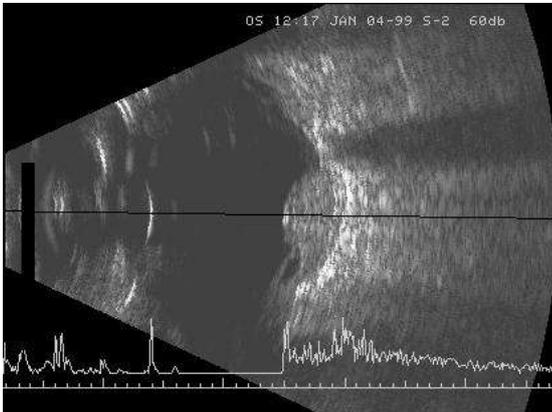


**OCT scan showing cystoid macular oedema**

### ***Ultrasonography***

With ultrasonography, high-frequency, inaudible sound waves are emitted into the eye. These waves bounce off any tissue surface back towards the probe, which measures the 'loudness' of the reflected sound and the time taken for the sound to travel into the eye and back again. The intensity of the reflected signal gives an idea of the 'hardness' of the reflecting tissue. The time taken for the reflected signal to be received gives an indication of the distance travelled by the sound.

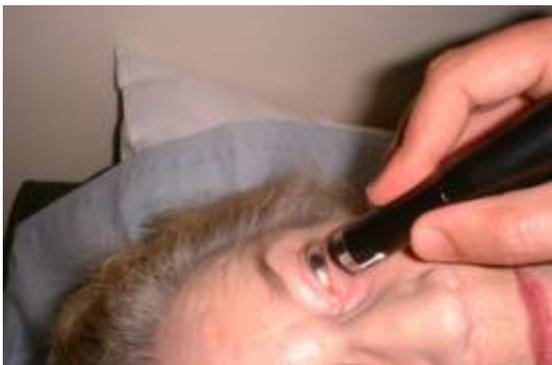
A-scan ultrasonography produces a linear signal, with a series of waves, which reveal the consistency of the tumour. With B-scan ultrasonography, the beam sweeps the eye from side to side, producing a visual slice of the eye and a good idea of the size and shape of any tumour in the eye.



**Ultrasonogram, with tumour at back of eye, next to nerve**

Ultrasonography has several applications in assessing an eye with a tumour:

- If the media are opaque, it enables the tumour to be detected.
- Ultrasonography can also reveal tumour extension outside the eye.
- By demonstrating a mushroom shape, ultrasonography can help establish the diagnosis.
- With calipers, it is possible to measure tumour thickness and basal diameter. These measurements are useful when selecting treatment and measuring how a tumour is growing or regressing over time.



## **Ultrasound probe in position**

The front of the eye is assessed with a special high-frequency probe, which requires the use of a small eye-bath or a sheath filled a clear jelly-like fluid.

## ***Magnetic Resonance Imaging***

MRI is performed by emitting pulses of magnetism through the body so that all the atoms spin in the same direction thereby giving rise to electrical fields, which are measured and converted into images. This method produces very clear pictures of the eye, with different tissues showing different degrees of brightness.

## ***Computerized tomography***

CT scans are obtained by passing very fine x-rays through the head from different directions and then reconstructing the results to create an image 'slice' of the eye.

MRI and CT scans do not usually provide more information than ultrasonography, which is more convenient and less expensive.

## ***Biopsy***

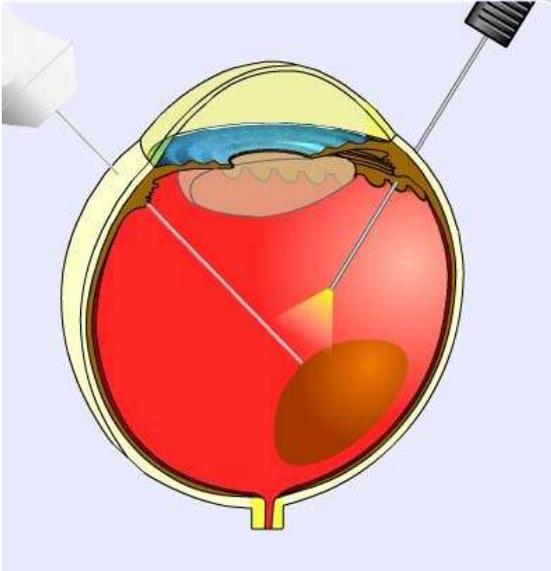
Biopsy is useful for:

- Making the diagnosis, when this remains uncertain after clinical examination and ultrasonography;
- Confirming a suspected diagnosis of intraocular metastasis (i.e., tumour travelling to the eye from elsewhere), also indicating the most likely site of origin, if this is not known; and
- Determining whether an intraocular melanoma has the capacity to metastasize to the liver and other parts of the body.

## **Trans-vitreous biopsy**

This is performed by passing either a fine 25-gauge needle or a 25-gauge vitreous cutter (like a vacuum cleaner) through the eye into the middle of the tumour and

taking small samples for analysis. The vitreous cutter gives a better yield so that it is more reliable.



#### **Choroidal tumour biopsy with 25-gauge vitreous cutter**

#### Trans-scleral fine needle aspiration biopsy

A fine, sharp needle is passed through the wall over the eye directly into the tumour to obtain a tiny sample.

#### Incisional biopsy

Incisional biopsy is performed by removing a small sample with scissors or a scalpel. With intraocular tumours, this is a more difficult procedure than trans-ocular biopsy and is usually performed under general anaesthesia, with moderate lowering of the blood pressure. With conjunctival tumours, this is a small operation, performed under local anaesthesia on an outpatient basis.

#### Excisional biopsy

Excisional biopsy involves total removal of the tumour, thereby providing both a

diagnosis and a cure. It is mostly performed if local resection would be the treatment of choice in any case. In exceptional situations, if the eye is blind and painful the most practical solution is to remove the eye and to establish the diagnosis by pathological examination.

Biopsy of intraocular tumours is associated with a number of risks, which include:

- An inconclusive result, either because the sample taken was too small or because technical problems in the laboratory. An inadequate sample is more likely with very small tumours.
- Seeding of intraocular tumour onto the surface of the eye. This is very rare.
- Intraocular haemorrhage, which is common but mild, usually resolving spontaneously over a few weeks.
- Other rare ocular complications, such as retinal detachment and intraocular infection.

The benefits of biopsy include:

- Making an immediate diagnosis so that treatment can be given without delay, also avoiding unnecessary scans.
- Providing reassurance when an intraocular melanoma is most unlikely to affect general health
- Enabling special investigations to be performed and other care to be provided when an intraocular melanoma is life-threatening.

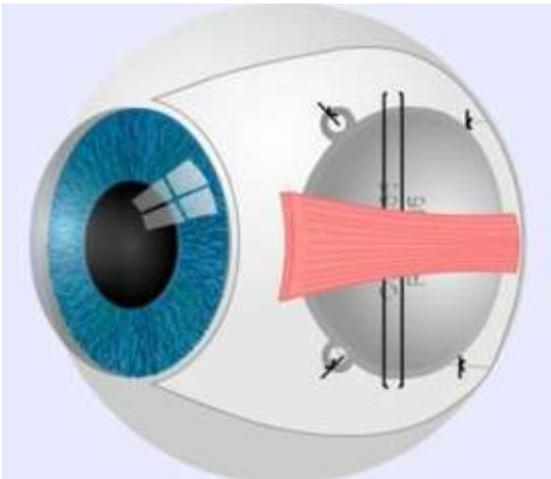
# 5

## Treatment of ocular tumours

This chapter gives an overview of the methods available for treating ocular tumours, benign and malignant. More detailed information will be given to you once the most appropriate form of treatment for your particular tumour has been selected.

### *Plaque radiotherapy*

This treatment is indicated for selected choroidal melanomas, some malignant conjunctival tumours and some tumours travelling to the eye from elsewhere (i.e. metastases). It enables a high dose of radiation to be focused onto a small area and has the advantage of being completed in a few days.



### **Ruthenium plaque sutured to the eye wall directly over the tumour**

The radiotherapy is administered by means of a saucer-shaped plaque, which has an inner, concave radioactive surface and an outer, convex protective shield.

The treatment involves:

- A 45-minute operation under general anaesthesia, during which the plaque is placed against the

wall of the eye directly over the tumour and held in place with sutures. If possible, a biopsy is performed immediately before the radioactive plaque is sutured to the eye.

- A second, 25-minute operation under general or local anaesthesia. The plaque is removed between one and seven days later, once the appropriate dose of radiation has been delivered.

We can select between ruthenium plaques, which are suitable for tumours up to approximately 5 mm thick, and iodine plaques, which can treat tumours up to 9 mm thick (albeit giving a higher dose of radiation to normal ocular structures). Ruthenium plaques are available within a day, whereas iodine plaques need to be constructed for each patient and this takes up to six weeks.

This radiation does not travel beyond the eye so there is no risk of hair loss or other general problems. There is no radiation once the plaque is removed.

We have developed techniques for positioning a ruthenium plaque eccentrically in relation to the tumour so that we can increase the dose of radiation to the tumour without a corresponding increase in the radiation delivered to optic nerve and fovea.



**Good result after plaque radiotherapy, with conservation of 6/6 vision ten years after treatment. The black area is dead tumour (i.e., ‘pile of soot’) and the white area corresponds to the plaque’s location, which was eccentric in relation to the tumour.**

### ***Proton beam radiotherapy***

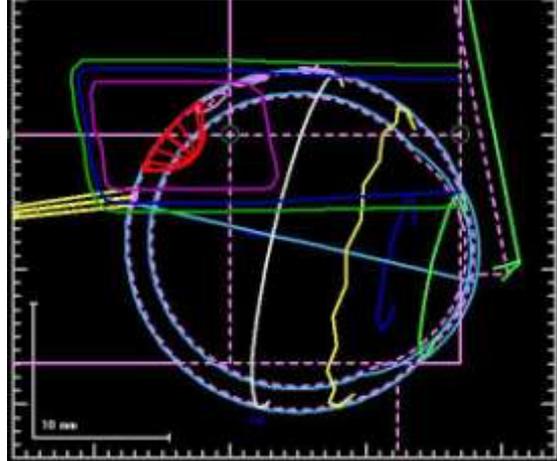
This treatment is selected when the tumour is not suitable for the more convenient plaque radiotherapy, that is, small intraocular melanomas near the optic nerve, some choroidal haemangiomas, iris melanomas, and some large intraocular melanomas.

The treatment involves:

- A 45-minute operation under general anaesthesia, to suture four tiny tantalum markers to the wall of the eye, at known distances from the tumour margins;
- Treatment planning for half a day at Clatterbridge Centre for Oncology (CCO), a few weeks after the marker insertion;
- A few weeks later, a course of radiotherapy at CCO, with one 60-minute session on five consecutive days;
- Tumour biopsy after completion of the radiotherapy; and

- An examination at your local eye hospital about four weeks after the radiotherapy.

The radiotherapy at CCO is painless.



**Plan for proton beam radiotherapy**

### ***Stereotactic radiotherapy***

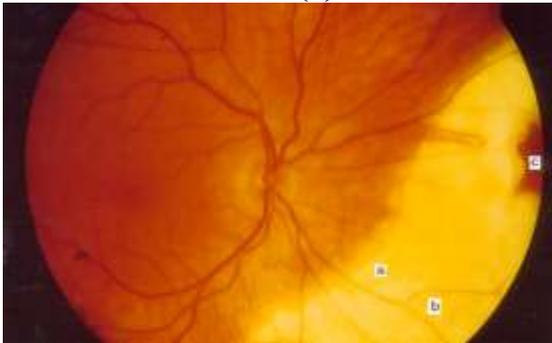
This treatment involves directing radiation at the tumour from several directions so as to maximise the dose of radiation within the tumour while minimising the radiation delivered to surrounding healthy tissues. This treatment is not performed at our hospital because we prefer other methods.

### ***Trans-scleral local resection***

Trans-scleral local resection involves removing the tumour through a large trapdoor in the wall of the eye. To prevent bleeding, the intraocular pressure is lowered, using hypotensive anaesthesia, monitoring the brain and heart using special equipment. Each trapdoor operation takes about two or three hours. This is difficult surgery and mostly reserved for large tumours that tend to become toxic to the eye after radiotherapy. If local resection is performed in the first instance, a radioactive plaque is usually placed over the treated area to reduce the chances of tumour recurrence, and this is done either at the end of the operation or a month later.



**Right eye showing choroidal melanoma before local resection (a)**



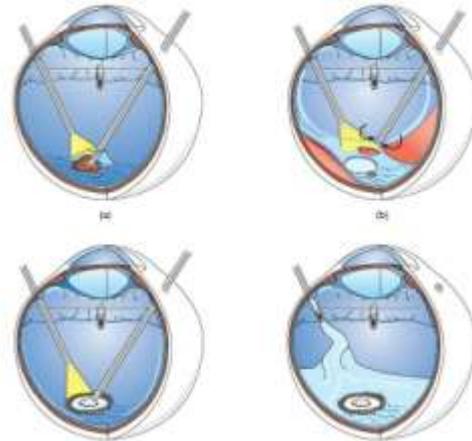
**Post-operative view showing (a) inner surface of white sclera, (b) retinal vein, and (c) small residual haemorrhage.**

### ***Trans-retinal endoresection***

The tumour is cut into fragments, which are sucked up a fine, metal tube that is passed through a hole in the retina. Laser treatment is administered during the operation to ‘weld’ the retina in place. The eye is filled with silicone oil to hold the retina in place until scarring has welded the retina in position. This operation is usually performed to remove moderately sized tumours after radiotherapy if they become toxic to the eye. In rare cases when we perform endoresection as the first procedure, we administer laser treatment and perhaps radiotherapy to prevent tumour recurrence.

The treatment involves:

- a two-hour operation under general anaesthesia, and
- after approximately 12 weeks, a 30-minute operation under local anaesthesia to remove the silicone oil, often with cataract surgery at the same time.



**Endoresection involves (a) tumour removal, (b) temporarily filling the eye with air, (c) laser treatment, and (d) filling the eye with silicone**

### ***Conjunctival excision***

Discrete tumour nodules on the surface of the eyeball can be removed surgically, if not too extensive. This can be done under local or general anaesthesia.

### ***Transpupillary thermotherapy***

Laser treatment involves heating the tumour for about one minute, using an infrared laser beam. The treatment lasts about half an hour and is delivered under local anaesthesia on an outpatient basis.

This treatment is suitable for small tumours, when there is uncertainty as to whether the lesion is a benign mole or a malignant melanoma. It is also useful for melanomas that are leaking excessive amounts of fluid after previous radiotherapy.

### ***Cryotherapy***

Very thin tumours on the surface of the eyeball can be given ‘freezing treatment’, using either a spray of liquid nitrogen or a special pencil-like device. This treatment can be administered under local or general anaesthesia.

### ***External beam radiotherapy***

External beam radiotherapy is indicated for some tumours travelling to the eye from another part of the body (i.e., metastases). These tumours respond to doses of radiation that are usually low enough to be well tolerated by the whole eye. The equipment required for this treatment is available at most hospitals. To reduce complications, the treatment is given in small doses over days or weeks.

### ***Photodynamic therapy***

With this treatment, a dye called Verteporfin is injected into a vein in the arm, so that it circulates around the body and through the tumour. After a few minutes, an infra-red laser is directed at the tumour for about 83 seconds and this activates the dye so that it kills the tumour. This treatment is painless. It is necessary to stay out of bright sunlight for about two days afterwards.

Photodynamic therapy is very effective for choroidal haemangiomas and other tumours arising from blood vessels. There is some evidence that this treatment may also be useful for some other tumours, such as melanoma and vasoproliferative tumour.

### ***Topical chemotherapy***

If too extensive for surgical removal, very thin conjunctival tumours on the surface of the eye can be treated with special drops ('weedkiller'), consisting of Mitomycin C or 5-FU. These drops are administered on an outpatient basis, with each course lasting between four and seven days. It is usually necessary to repeat the course of treatment every two or four weeks, about three or four times.

### ***Intraocular injections***

Intraocular injections, which are quite painless, are given under local anaesthetic. These include steroids for inflammation, chemotherapeutic agents such as methotrexate for lymphoma, and anti-

angiogenic factors (e.g. Avastin), which shrink blood vessels. Avastin was developed for intravenous administration for treatment of cancer spreading to the liver from the large bowel. It is not licensed for intraocular administration but has nevertheless been found to be safe and effective for conditions such as diabetic retinopathy and age-related macular degeneration. We have had some very good results in patients with irradiated intraocular melanoma and with a variety of other tumours. Ocular complications such as haemorrhage and infection are rare. Care has to be taken with patients having high blood pressure, angina and kidney disease. The risks and benefits are discussed in detail and are listed in an information sheet given to all patients undergoing this treatment.

### ***Enucleation***

Removal of the eye is indicated when the chances of conserving a useful eye are not good enough to justify the risks involved.

The operation is usually performed under general anaesthesia. A long-acting anaesthetic injection is given to minimize pain during the initial post-operative period. The enucleated eye is replaced by a ball implant. The eye muscles are sutured to this implant so that the artificial eye will move with the fellow eye. At the end of the operation a transparent 'conformer', similar to a rigid contact lens, is placed in the socket. About ten weeks after surgery, this is replaced by a 'tailor-made' permanent artificial eye, at the patient's referring hospital. The artificial eye is like a coloured contact lens, painted to match the fellow eye. This usually gives a good cosmetic result.

To avoid any risk of Creutzfeldt Jacob Disease (CJD) (i.e., a human form of 'mad-cow disease') the operation is performed with disposable instruments and tissue transplants are not used.

A district nurse will visit you daily to help you with the conformer. If any problems arise, you can phone the Specialist Ocular Oncology Nurse (i.e. Key Worker) at any time (0151 706 3976).

### ***Exenteration***

In very rare instances it is necessary to remove not only the eye but also the surrounding tissues and the eyelids. A special cosmetic prosthesis is made after the operation.

### ***Multidisciplinary Meetings***

Meetings with staff from different disciplines (e.g. ophthalmologists, nurses, pathologists, radiotherapists, oncologists, etc) are held:

- at the end of each new patient clinic, to discuss diagnosis and treatment plans;

- before proton beam radiotherapy to agree therapeutic strategy;
- after biopsy, local resection or enucleation, to discuss findings of microscopic tissue examination (i.e., pathology);
- after any adverse radiotherapy events, to determine whether complications might be avoided;
- once a year, with all members of the team present, to announce new developments and review policy.

Operational meetings are also held regularly to discuss organizational matters, equipment, and working protocols.

# 6

---

## Your hospital admission

### *Treatment schedule*

We try to perform treatment the day after your arrival at our centre. This is to reduce the amount of travel between your home and the hospital, if you live far away from Liverpool. We also assume that you would like to get your treatment over and done with as quickly as possible so that you do not worry with anticipation and so that you can quickly return to normal life. If you do not wish to start treatment immediately, we can easily postpone your operation.

If we receive more patients than we can treat on a single day we need to prioritise patients according to the size of the tumour and the distance that they would need to travel, should surgery be delayed. Tumours rarely change much from week to week so a delay of a few days or weeks should not worsen the outcome.

If your operation is scheduled for the afternoon as a day case, we will still require you to arrive at our unit in the morning and this is in case there are any cancellations or changes to the theatre list.

### *Pre-operative Investigations*

If you are to be admitted to hospital, you will first have a number of investigations. These include:

- Haematological studies (ie, “full blood count”), to exclude anaemia;
- Serum biochemistry (ie, “U’s and E’s and LFT’s”), to check liver and kidney function; and
- Electrocardiography (ie, “ECG”), to check your heart.

These tests are performed mainly to ensure that you are fit for general

anaesthesia. Scans for tumour in other parts of the body are performed selectively (e.g., if an intraocular melanoma is large).

You will be asked to sign a consent form, which specifies the nature of the operation and the eye to be treated. If the operation involves removal of the tumour or the eye, then you may be asked for permission to use a small tumour specimen and blood samples for research purposes. You are of course under no obligation to participate in any studies.

Please do not leave the clinic until you have had all investigations and completed the necessary forms.

### *Admission to Ward*

You will be admitted to our inpatient ward (9Y) or the daycase unit on the ground floor. This will happen immediately after your clinic visit or on the day of your operation. A nurse will welcome you and show you to your bed. You will be asked more questions about your general health, medications, allergies, and other matters.

A named ophthalmic nurse will be allocated to your care, to look after your individual needs. All nurses and doctors wear name badges at all times.

The ward is divided into several rooms, with each multi-bed room housing patients of the same gender. There are a few single rooms for patients requiring isolation.

You will be visited by our specialist ocular oncology nurse. She will see how you are settling into the hospital and will answer any questions you may have.

The Surgical Trainee (ST) will perform a full clinical examination and will prescribe any of your usual medications that you need to continue taking during your stay in hospital.

This is another opportunity for you to ask any more questions that come to mind. At the appropriate time, you will be shown how to instill eye drops.

As soon as possible, a doctor or nurse will obtain the results of all investigations, ensuring that these are adequately documented in your casesheet.

The anaesthetist will visit you before your operation. The aims of this visit are to ensure that you are fit for anaesthesia and to explain to you the details of your anaesthetic. The results of your ECG and any other relevant investigations will be reviewed. You will be asked about any previous anaesthetics you have received. Please feel free to ask any questions.

Once you have seen the anaesthetist you can leave the hospital for a few hours, if you wish. Before you do so, please check whether you are to be seen by the anaesthetist as your operation may need to be postponed if you miss this assessment. Also be sure to inform the nursing staff of your plans and to agree upon a time when you should return. Please also give them your mobile number if you have one.

Visiting times are 2.00-4.00 pm and 6.00-8.00 pm, although special arrangements can be made at the discretion of the nurse in charge. A limit of two visitors per bedside should be observed. Children are allowed only if visiting a close family member and are the responsibility of the accompanying adult.

### ***Pre-operative Ward Round***

On the day of your operation, you will be visited by an ophthalmologist to check any details and to ensure that all is well.

If you are to have a general anaesthetic, you will need to fast for at least six hours beforehand, that is, from midnight if your operation is scheduled in the morning and from about 7 am if you are due to have your operation in the afternoon. While fasting, you must have nothing at all to eat or drink.

If the tumour is at the back of the eye, we will dilate the pupil of the eye to be operated upon.

### ***The anaesthetic room***

When it is time for your operation, you will be moved to the anaesthetic room and transferred from your bed to the operating table.

The operating department assistant (ODA) will attach electrical leads to your chest and arms to monitor your heart. If local resection is to be performed, additional leads will be attached to your head for brain monitoring. All leads are attached to the skin with adhesive tape.

The anaesthetist will put you to sleep by giving you an injection on the back of your hand.

Once you are anaesthetised, the anaesthetist will maintain your airway by placing either a laryngeal tube or mask at the back of your throat. This is to ensure that you have no difficulty breathing during the operation.

If the eye is to be removed, a mixture of local anaesthetic with adrenaline solution is injected behind the eye to reduce bleeding and post-operative pain.

### ***The operating theatre***

The electrical leads and a breathing tube will be linked up to the anaesthetic machine so that your pulse, blood pressure, oxygen level and your heart will be monitored continuously.

If you are to receive hypotensive anaesthesia, which is necessary for local resection of the tumour (ie, ‘trapdoor operation’), then your brain activity will be monitored continuously. All these precautions ensure that there is a healthy exchange of fresh air through your lungs and a good circulation of blood throughout your body while you are under anaesthesia.

The anaesthetist will stay with you throughout the operation.

Your identity will be confirmed by a nurse, by checking your wrist band and the signed consent form, which will also be used to check that the correct type of operation is to be performed.

If you are to have a local resection, the lashes will be trimmed (These re-grow back to normal in six weeks).

The skin around the eye to be operated is cleaned with an antiseptic solution called Betadine, which contains iodine (so please be sure to let us know if you are allergic to iodine).

The eye not to be operated on is taped shut, so that it is well protected. A sterile drape is placed over your head and upper chest. This has a small window, which is sealed with an adhesive, transparent film. This film is cut with scissors to expose the eye, which is held open with a speculum.

At this point (and not before), the eye to be operated upon is examined by the surgeon by ophthalmoscopy so that the tumour is located. This makes it absolutely impossible to operate on the wrong eye.

During the operation, the surgeon is assisted either by another ophthalmologist or by the specialist ocular oncology nurse.



### **Surgery in progress**

A scrub nurse, also wearing sterile gloves and gown, looks after the instrument trolley, passing instruments as necessary to the surgeon and the assistant.



### **Scrub nurses at work**

A ‘runner’ is also present in the theatre in case any items need to be transferred to and from the instrument trolley, to collect any tumour specimens and to ensure that everything runs smoothly.

The ODA is at hand to help with the operating microscope, operating lights, video recorder and any other equipment.

There may occasionally be visitors, such as ophthalmologists from other hospitals or medical students.

A video of the operation may be taken for teaching purposes, with your consent. This will not be shown without your consent if there is any chance that you might be recognised.

### ***The Recovery Room***

At the end of your operation, you will be transferred back to your own bed and taken to the recovery room, where you

will be monitored by your own nurse (i.e., one nurse per patient). The anaesthetist will also be present in the operating suite until you regain consciousness.

### ***The Ward***

Once you have recovered from the anaesthetic and are comfortable, two porters and a nurse will take you to your ward.

In the ward, a nurse will look after you and will give you any medications that you require for the relief of pain or nausea.

After some types of surgery (e.g., endoresection and local resection), it may be necessary for you to remain postured for the first day, for example, lying on your left side with your left cheek against the pillow. This is so that any retinal haemorrhage will gravitate away from the fovea and not damage your vision.

### ***The Post-operative Ward Round***

Once a day, and more often if necessary, an ophthalmologist will examine your eye. This is mostly to ensure that there is no infection and to check that the intraocular pressure is normal.

Routinely, all patients are examined first by a surgical trainee between 8.15 am and 8.45 am, and then by the consultant between 8.45 am and 9.00 am. Please be sure to stay by your bed between these times.

Drops will be given to you to keep your pupil dilated. This is to prevent discomfort and to enable the back of your eye to be examined. Antibiotic and steroid drops will also be given to prevent infection and inflammation.

If you have a radioactive plaque in place, special precautions are necessary to prevent persons around you from being exposed to unnecessary radiation. These include:

- Placing you in a single room;
- Displaying a hazard notice on the door of your room;
- Covering your eye with two shields, to block any stray radiation from escaping.

Do not be alarmed by all these precautions. The amount of radiation is quite minimal.

You do not need to wear a cover over your eye if there is no one else in the room.

We recognise that the period following diagnosis and treatment can be difficult. It is quite normal for people to feel a range of emotions at this time. A health psychologist or specialist nurse will therefore visit you on the ward. This is to discuss any worries so that these can be addressed without delay. If the need for more support is identified, arrangements will be made for you to be telephoned after you leave the hospital or to receive further care close to home.

### ***Discharge from Hospital***

You can expect to return home one or two days after your operation.

When the time comes for you to be discharged from hospital, you will be given a supply of any drops and oral medications that are required. These will need to be obtained from the hospital pharmacy. We order these medications a few days in advance so that you will not be kept waiting when it is time for you to return home.

You will also be given a note to take to your general practitioner, an information leaflet and a satisfaction questionnaire (to be completed anonymously). Please return the questionnaire, even if there is anything you are not satisfied with.

Please ask the ward nurse for a 'Sick Note' if you need one. If an urgent

appointment is needed at your hospital, this will be arranged and you will be informed of the date and time of the appointment before your discharge from the ward.

The consultant will send your ophthalmologist a discharge letter with all relevant information about your condition. Any follow-up arrangements will be mentioned in the letter so that your hospital can send you an appointment if necessary. Copies of this letter will be sent to your general practitioner and to you. With your consent, a copy of the letter is also sent to your optometrist.

As soon as the results of any pathology studies are received, these are sent to your ophthalmologist and general practitioner together with a covering letter explaining the significance of the results and suggesting further management as appropriate. We do not send patients copies of these reports, which we feel should be discussed in person. You will receive a letter with appropriate instructions. We usually need to wait a few weeks for the laboratory results to become available to us.

### ***Convalescence at Home***

When you return home, you may feel surprisingly tired and you may even feel a little 'low' for a few days. These feelings are quite normal, bearing in mind the stress of the previous few weeks, the inactivity in hospital, and having to cope with one or two general anaesthetics.

Your convalescence is a time for peace, good food, gentle exercise and coming to

terms with things, taking advantage of whatever help is available from family, friends and various care workers.

You can wash your hair and take a shower or bath at any time as long as you are careful to avoid water splashing into your eye, at least for the first four or five days. It should be safe to go for a walk and to resume mild exercise after one or two days, but more strenuous activities such as running may need to be postponed for one or two weeks, depending on the operation.

Your operated eye will probably be quite red and tender for the first week or two, but should settle down, especially if you remember to take your medications as instructed. Until healing occurs, your eye will be particularly sensitive to irritants such as soapy water, chlorinated water in swimming pools, and smoke.

Within two weeks of your return home, you will receive a telephone call from our specialist ocular oncology nurse in case you have any problems. If you have any questions, however, you can ring her up at any time (Tel: 0151 706 3976). Similarly, if you have any worries or concerns about how you are coping, our specialist nurse can get you in touch with our health psychologist.

If the specialist ocular oncology nurse or the health psychologist is not available when you phone, please leave a message on the answer-phone and you will receive a reply as soon as possible

# 7

---

## Follow up

### *Follow-up at home hospital*

You should be examined by an ophthalmologist about one week after local resection or endoresection and within a month of any other procedures (i.e., plaque radiotherapy, enucleation).

Unless you live very close to Liverpool, this examination will be performed at your own hospital.

Some general ophthalmologists are anxious about having to look after a patient who has undergone treatment for a tumour, because, quite understandably, they may not be very familiar with the surgical techniques involved. Nevertheless, all your ophthalmologist needs to do at this early stage is to ensure that there is no infection, no raised intraocular pressure and, indeed, no sign of any other complication that would be common to any eye operation.

After radiotherapy or phototherapy, the tumour does not usually begin to regress for several weeks or months. This is why follow-up assessments at our centre are delayed for six or nine months after such treatments.

If it is likely that treatment is required before this time, for example, after local resection or endoresection, then arrangements will be made for you to attend our centre as necessary.

Ocular examination is recommended every six months for the first six years then once a year for several years and eventually once every 18 months to two years for the rest of your life.

Initially, arrangements are made for these examinations to alternate between your local hospital and our centre. This system of alternating examinations is designed to:

- ensure that the ophthalmologists at your hospital keep in touch with your progress and become familiar with your condition;
- make it easier for the ophthalmologists at your hospital to take over full responsibility for your care when the time comes for you to stop attending our centre;
- reduce the need for you to travel long distances between your home and our hospital, if you live far from Liverpool; and
- reduce the number of patients attending our follow-up clinics, making it possible for a consultant to see every patient at every clinic visit.

### *Follow-up at the Oncology Centre*

Our follow-up clinics are held on Thursdays (morning and afternoon) and on Friday afternoons. We also have a Nurse-run clinic for patients who do not need to be examined by an ophthalmologist. The nurses are fully trained and can obtain immediate advice from a doctor if the need arises.

The procedure at our follow-up clinic is similar to that of your first consultation.

You will be registered at the reception desk. Next, the sift nurse will check your vision and, if necessary, dilate your pupils.

A surgical trainee or fellow will first ask you a number of questions, using a

structured questionnaire. These questions are designed to cover all possible symptoms and to get some idea of how worried you might be about tumour recurrence and spread. These questions are asked so that we can alleviate symptoms and discuss any of your worries. This is so that appropriate reassurance can be given if such fears are groundless (as they often are) or so that advice can be given if there is genuine cause for concern.

You will next have your photographs taken. We will ask you to sign a consent form for these images for teaching and research.

After your photography, you will be asked to wait until a consultant sees you. Unfortunately, this can be quite a long wait because the consultants routinely see all patients at every clinic, which means that the morning clinic rarely finishes before 1.30 to 2.00 pm. We have tried to reduce waiting times by spreading appointment times more evenly across the clinic session but this tended to result in slack periods in the early part of the clinic and a rush to catch up later on. It only needs one or two patients to arrive late, because of a train delay or congestion on the motorways, to disrupt the whole clinic.

The consultant will review the case notes with you, discuss any symptoms or concerns you might have, and examine your eye, if necessary also performing ultrasonography. If appropriate, he will compare the clinical findings with previous photographs. Next, he will discuss your results with you, answer any questions, dictate a letter to your ophthalmologist with a copy to your general practitioner and give you an appointment sheet to hand to the clerk at the reception desk.

The specialist nurse can speak to you in a quiet room if there are any matters you wish to discuss with her. You may also ask to meet our health psychologist.

You, your GP and any other practitioner involved in your care will receive a copy of your report, but it is not our current policy to send copies of letters from follow-up clinics to optometrists.

#### ***Discharge from our Centre***

You will be discharged from our centre when we feel it is safe for you to stop attending.



## After your discharge from our centre

We would like to continue to be involved in your care even after you have stopped coming to our follow-up clinics.

### ***Screening for metastatic disease***

If you have been treated for an intraocular melanoma you will be informed of your prognosis in an appropriate manner, depending on how good or bad the news is. Your GP and ophthalmologist will also be informed of the results.

Depending on your prognosis, plans will be made for your further care, which will be discussed with you. These may involve six- or twelve-monthly blood tests and liver scans. There are different types of scan, which include:

- ultrasound scans;
- magnetic resonance imaging (MRI), which can be performed with or without contrast and diffusion weighting; and
- positron-emission tomography (PET), mostly after liver tumours are found, to look for tumours elsewhere.

Compared to US, MRI is more sensitive, especially with contrast, but also more expensive.

### ***Treatment of metastatic disease from uveal melanoma***

A variety of treatments are available for metastatic disease from uveal melanoma and these include:

- systemic chemotherapy;
- intra-hepatic chemotherapy, delivered into the liver;
- surgical removal of liver tumours;
- radiofrequency ablation;
- ipilimumab immunotherapy;

- selective intrahepatic radiotherapy using Yttrium beads.

Please ask us for information about screening for metastasis and treatment of metastatic disease from uveal melanoma if these ever become relevant to your care.

We hope it will one day be possible to administer adjuvant therapy that can delay or prevent the onset of symptomatic metastatic disease.

### ***How we are informed of your progress***

We ask your general ophthalmologist to send us a copy of any letter to your GP. All relevant information is computerised in our database. This information is used to perform long-term studies, which are so important in evaluating our care.

### ***How you can get in touch with us***

We would all like patients to feel that they can get in touch no matter how many years have elapsed since treatment.

We routinely send a quality-of-life questionnaire to all patients on the anniversary of their first ocular treatment. This helps us evaluate our care, from the patient's point of view, so that future patients can be given appropriate advice when selecting treatment. Please make a special effort to complete and return this questionnaire, even if there seem to be an awful lot of difficult and strange questions.

### ***How we keep you informed of progress***

We have set up a website on the internet ([www.eyetumour.com](http://www.eyetumour.com)). This contains a copy of this guide and other information. There are also links to sites you might find useful.

## Frequently asked questions

---

### **Why was I sent to an oncology centre if my tumour was not malignant?**

The techniques used for diagnosing and treating benign tumours of the eye are similar to those required for malignant tumours. The appropriate facilities are not widely available because ocular tumours are rare, making it necessary to concentrate resources in only a few centres around the country.

### **If I have an ocular melanoma, what are my chances of survival?**

The chances of survival are usually good. They are related to:

- the size of the tumour at the time of treatment;
- whether the melanoma cells are spindle-shaped or round (ie, 'epithelioid');
- whether certain chromosomal abnormalities (e.g. 'Mono3') are present in the melanoma cells;
- whether or not certain changes have occurred in the supporting tissues within the tumour (i.e., 'closed loops');
- the rate at which the melanoma cells are dividing (determined by counting the number of dividing cells in forty high-power microscope fields).

### **Will my tumour grow significantly by the time I come to the oncology clinic in Liverpool?**

If the tumour is a melanoma, it is most unlikely to change significantly within a few weeks, so the delay of two weeks should not alter your chances of survival or of saving your eye and vision. Nevertheless, we try to see patients

quickly so as to minimize any anxiety as soon as possible.

If an ocular tumour is a metastasis, arising from a primary tumour elsewhere, then rapid growth commonly occurs, making treatment more urgent.

### **Why didn't the doctors at my local hospital explain to me what was wrong with my eye?**

Ocular tumours are rare and their treatment is highly specialized, so that some doctors prefer to leave all explanations to us.

### **Is the eye removed during surgery?**

Not unless it is to be removed permanently. This is because it is not possible to return the eye to its normal position once it has been removed. Access to the back of the eye for the insertion of markers or a radioactive plaque or for local resection is gained by temporarily detaching one or two muscles from the eye and gently turning the eye so that it looks sideways.

### **How long will I be in hospital?**

The time you spend in hospital will depend on the type of operation and the need for any intensive postoperative eye care. The discharge times are normally as follows:

- Same day as marker insertion;
- Same day as plaque removal or next day;
- One or two days after removal of the eye;
- The same day, if any procedure is performed under local anaesthesia (as after laser treatment or conjunctival biopsies (i.e., 'snips')).

If you have plaque radiotherapy, the time for which the plaque is left in place depends on:

- the size and nature of the tumour, and hence the dose required; and
- the age of the plaque, which influences the amount of radiation emitted per second.

This is usually between one and seven days.

### **What drops will I be given on leaving the hospital and for how long?**

You may be given any of the following:

- Chloromycetin or other antibiotic drops, to be taken four times daily for one week, to prevent infection;
- Betnesol or other steroid drops, to be taken four or six times daily for between four and twelve weeks, to reduce inflammation; and
- Atropine, cyclopentolate or other pupil-dilating drops, two or three times daily for between one and four weeks, to prevent painful spasm of the eye muscles. These drops may blur your vision.

### **What side effects can occur with these drops?**

Possible side effects include:

- Allergy, characterized by itching, redness and swelling around the eye;
- Blurred vision with pupil-dilating drops, because the focusing muscles are temporarily paralysed;
- Glaucoma in predisposed individuals if steroid drops are administered for several weeks.
- Ocular infection if long-term steroid drops suppress immunological defences.

If you develop any pain or redness after your return home, you should see your general practitioner, who would refer you to your ophthalmologist, if necessary. You can also telephone the specialist nurse

(0151 706 3976) or the ward (via the hospital switchboard at 0151 706 2000).

### **Will I be shown how to instill my eye-drops?**

The ward staff will show you how to put drops in your eye. If you have any difficulties, you can try to administer the drops lying flat on your back while looking up at the ceiling and resting the drop bottle on the bridge of your nose (taking care not to contaminate the nozzle of the dropper). If you have arthritis you can ask a ward nurse to provide you with a special appliance to help you instill drops safely, but please bring this matter to the nurse's attention as soon as possible so that there is enough time for this item to be obtained.

### **What are the side-effects of radiation?**

If you receive plaque radiotherapy or proton beam radiotherapy, any side-effects will be limited to the region of the eye itself.

Within the eye, these can include:

- Fluid leakage from the tumour, this fluid accumulating within or beneath the retina, causing retinal detachment;
- Closure of the blood vessels within the optic nerve or retina;
- Cataract;
- The formation of delicate blood vessels, which have a tendency to bleed into the eye; and
- The formation of blood vessels on the iris, which prevent fluid outflow from the eye, resulting in elevation of the intraocular pressure (glaucoma).

Outside the eye, these can consist of:

- Loss of lashes in the treated area;
- Redness of the eye;
- Watering or dryness of the eye;

Before your treatment, you will be told of the chances of developing any of these side-effects.

You should not lose your hair or develop any general side effects as a result of radiation.

### **Are side-effects of radiotherapy treatable?**

Healthy tissues such as the lens, optic nerve and macula (i.e. the central part of the retina) suffer ‘collateral damage’ if they receive an excessive dose of radiation (i.e. a ‘direct hit’). Visual loss from optic neuropathy or maculopathy is usually irreversible, whereas cataract is eminently treatable, usually with an excellent outcome.

Visual loss can also occur as a result of leakage of fluid and various noxious agents from the irradiated tumour (i.e. ‘toxic tumour syndrome’). These can be treated by:

- Laser treatment, which creates a ‘waterproof coating’ over the tumour surface;
- Intraocular steroid injection, which reduces inflammation and fluid leakage;
- Intraocular injection of an anti-angiogenic agent, which causes new vessels to regress, reducing fluid leakage and high intraocular pressure.
- Surgical removal of the toxic tumour, either through a trapdoor in the wall of the eye or by aspirating the tumour away with a mini-‘vacuum cleaner’.

### **Will I become radioactive when I receive plaque radiotherapy or proton beam radiotherapy?**

When a radioactive plaque is in place, there may be a very small amount of radiation around you. To protect other individuals, you: (1) will not be allowed to leave the ward; (2) will need to wear an

eye shield when you have any visitors; who should keep more than one metre away from you, and (3) will be isolated from anyone who may be pregnant and from children under the age of twelve.

There is no radioactivity remaining after your treatment is completed, that is, once the radioactive plaque is removed or once the proton beam is switched off.

You may wish to purchase TV cards, telephone vouchers, and other items such as magazines before your operation. Hospital volunteers would be able to buy small items from the hospital shop and can be contacted by the ward staff.

### **If I have insertion of tantalum markers for proton beam radiotherapy, will these ever need to be removed?**

No, unless they are placed near the front of the eye and if they cause irritation to the overlying conjunctiva, in which case they can be removed under local anaesthesia.

### **How much pain will I experience?**

We will give you whatever medications are necessary to control pain. Our usual measures for dealing with this problem include:

- Paracetamol, ibuprofen or other oral analgesics, to be taken every six hours;
- Infiltration of the eye with a long-acting local anaesthetic, administered during your operation;
- Strong agents, such as morphine, if pain is severe.

Previously, painkillers were only offered on request whereas now we prefer to administer these agents every six hours whether or not there is any pain, so as to prevent pain from developing in the first place. You may be asked to score the degree of pain you experience, so that we can improve our care.

**If I have a melanoma, aren't my chances of survival better if my eye is removed than if it is conserved?**

Several studies have shown that as long as long as the tumour is destroyed, the chances of survival are about the same whether the eye is removed or whether it is saved.

**What is meant by 'conservative treatment' and is such treatment more 'old-fashioned' than radical treatment?**

Conservative treatment is any kind of treatment that aims to conserve the eye and vision. Radical treatment refers to removal of the eye. Nowadays, conservative treatment has largely superseded radical treatment.

**Is it possible to remove or treat the wrong eye?**

To prevent the wrong eye from being treated, we always tape the normal eye shut, then sterilize the skin around the abnormal eye using a yellow disinfectant, then cover the face with a drape containing a small window, placing this window over the abnormal eye, and then we examine the eye, by ophthalmoscopy if necessary, not proceeding with the surgery until the tumour is seen. This protocol makes it impossible to operate on the wrong eye.

**What should I bring with me to the hospital?**

You should bring:

- All your medicines and drops;
- Dressing gown;
- Slippers;
- Underwear;
- Toiletries;
- Hairbrush or comb;
- Toothpaste and toothbrush;
- Soap and towels;
- Shaving equipment.

If you use any of the following:

- Spectacles or contact lenses;

- Hearing aid;
- Walking stick;
- Special shoes;
- Zimmer frame.

If you wish, you can bring any of the following items:

- Books/magazines;
- Knitting;
- Writing materials;
- Personal stereo;
- A small amount of money;
- A magnifying lens.

**What should I not bring with me to the hospital?**

You should not bring:

- large amounts of money;
- valuables;
- food requiring refrigeration;
- alcohol.

The hospital does not accept liability for loss of or damage to any of your personal possessions. If ambulance transport is required, only one item of luggage will be carried on the ambulance.

**Will I be isolated when I am in hospital?**

You will not be isolated unless:

- (1) you are treated with a radioactive plaque; or
- (2) you develop a severe ocular infection (which is extremely rare).

**Where can my accompanying relatives stay while I am in hospital?**

If possible, your relatives will be accommodated in Royal Chambers, across the street from the hospital. If this is full, we will organize on your behalf a room at a nearby hotel.

**I note that I am being seen at the Specialist Eye Research Centre (SERC). Does this mean that I am a sort of 'guinea pig'?**

No. The concept of SERC is to provide special facilities so that patients can benefit from the latest developments in ophthalmology and ocular oncology, safely and efficiently. With any new treatment it is especially important to take special precautions to minimize any risks and to detect any side-effects without delay so that best possible results are achieved.

### **Can I drive a car after my treatment?**

You can drive a car if you can read a numberplate from the legal distance (20.5 metres), even with one eye. You cannot drive with double vision, unless one eye is covered. If resident in the UK, you must inform your insurance and the DVLA of any severe and permanent visual loss. For further information (e.g. if you have a special licence), you can contact the DVLA by phone (0300 790 6801) or visit: [www.direct.gov.uk/DrivingAndMedicalConditions](http://www.direct.gov.uk/DrivingAndMedicalConditions)

### **Can I get help from LOOC after I have been discharged from the Royal Liverpool University Hospital?**

You can phone our specialist nurse or write to us with any questions or difficulties even many years after being discharged from our care. We will do all we can to address any problems.

### **How have donations been used?**

Donations to the **Eye Tumour Research Fund** have recently been used for the following purposes:

- Ocular lymphoma research. This research will enable us to determine whether or not an ocular lymphoma is likely to spread to different parts of the body.
- Statistics for developing methods for predicting survival after treatment of uveal melanoma). This work now enables us to inform patients and their practitioners whether or not their

melanoma is life-threatening and to advise on further specialised care. To our knowledge, we are the first worldwide to offer this personalized service to patients with intraocular melanoma.

- Cytogenetics research for understanding the genetic ‘clockwork’ regulating the behaviour of uveal melanomas. This work makes it possible for us to grade the degree of malignancy of ocular melanomas so that we can plan patient care appropriately.
- Purchase of Panoret camera and lease of Optos camera for the ocular oncology clinic. These cameras enable us to monitor tumours more reliably and are also useful for teaching purposes.
- Purchase of Konan specular microscope. This instrument enables us to examine the cells lining the inner surface of the cornea, to determine whether our treatment is causing invisible harm to this delicate part of the eye.
- Purchase of Eyecubed ultrasound machine for examining intraocular tumours, enhancing diagnosis, treatment planning and follow-up.
- Purchase of laboratory equipment for performing genetic analysis of ocular tumours.
- Purchase of video camera for recording surgical procedures, for teaching purposes.
- Funding of scientists performing research into genetic abnormalities of uveal melanoma.

We do not ask our patients for donations until they have stopped coming to our clinic and this is so that they do not feel obliged to contribute.

# Behind the Scenes

## Research

---

Research is of vital importance in preventing and treating disease. Besides treating our patients we are also expected to learn as much as possible from our unique experience and to share our findings with the rest of the world. We, and therefore our patients, benefit greatly from the teachings of others and we reciprocate by sharing our own discoveries in a similar way.

In general, research is conducted in the following way:

1. Observations are meticulously recorded, taking care to ensure that the results are not distorted by including some bits of information and leaving out others.
2. The data are analyzed statistically to determine whether the results are genuine or caused by chance.
3. Whenever possible, the mathematical results are supported by photographic evidence, so that any message is easily understood. If it is necessary to publish a photograph of a face, then parts of that face are either blotted out to prevent the patient from being recognisable or, if this is not possible, the patient's signed consent is requested. We obtain signed consent from all patients, whether or not they can be identified from the photographs.
4. Any important finding is broadcast to other interested workers by lectures at conferences and in other hospitals, publications in textbooks and scientific journals, and, increasingly, on computer programs and over the internet.

Several precautions exist to safeguard the rights of patients. Everyone working with

patient data has a legal duty to keep all information confidential. Any details that enable patients to be identified outside our hospital are removed. Before any research project can be started, it has to be approved by the Local Research Ethics Committee. This independent committee ensures that the research is feasible, well planned and worthwhile. It checks that the project is safe and that any risks are fully justifiable when considered in relation to the potential rewards. It also reviews any patient consent forms to confirm that patients participating in the study are given every opportunity to choose sensibly whether or not they should participate.

### *Clinical research*

The clinical research that we tend to perform in Liverpool consists of (1) evaluating different forms of treatment and (2) case reports.

Our centre provides special opportunities for research. Firstly, it is one of only half-a-dozen centres worldwide where more than 250 new patients with ocular melanoma are treated every year. Secondly, whereas other centres tend to offer one or perhaps two different kinds of conservative treatment, we can evaluate all established forms of treatment. Thirdly, our database contains one of the largest collections of information on ocular melanoma in the world.

The database was first established in 1985 and has continued to develop with the help of professional software consultants. Since 1987, this database has been maintained by a succession of data managers, who have ensured that the database is as complete as possible. A key to the success of the database is the way in which it is in constant daily use so that any errors

quickly come to light. The database is used by our secretary for writing letters, organizing clinics and theatre lists. It is also used by our specialist ocular oncology nurse, when she needs to communicate with patients or when a new patient asks to speak to a previously treated patient. It has often proved invaluable in patient care, for example, if the casesheet is not available when a referring ophthalmologist phones with a query about a patient. Information is collected and stored indefinitely so that long-term outcomes can be analysed.

We have good collaborative links with the NHS Cancer Registry. We inform the registry of any new patients with a malignant ocular tumour such as melanoma so that it is possible for epidemiologists to study the incidence of these tumours across the country. If any of our patients pass away, the cancer registry automatically informs us of the date and cause of death so that we can analyse our results.

According to the Data Protection Act, every patient has the right to view any information held about him or her. Strict guidelines exist to ensure that patient confidentiality is respected at all times and that any results are published with full patient anonymity.

Whilst there is no problem obtaining patients' consent prospectively for specific studies, the situation is more difficult when we wish to perform new research using old data and tissues collected many years previously. This is because it is difficult or impossible to get in touch with all the patients to obtain consent. To alleviate this problem, we have prepared a form that would enable current patients to give consent for data to be stored indefinitely and used in future research on topics that cannot yet be foreseen. These studies will be performed according to regulations existing at the time and under

the supervision of the Local Research Ethics Committee.

### Research Topics

Our clinical research has tended to report the results of treatments. Outcomes such as survival, conservation of the eye, preservation of vision, tumour control and quality of life are correlated with pre-treatment characteristics (i.e., 'variables') such as patient age, pre-treatment vision, tumour dimensions and so on. These studies have enabled us to inform other specialists about what can be achieved when a patient presents with a particular problem. It has also made it possible for us to advise patients on their own prospects for success after a particular treatment, so that they have been able to select the best treatment for their own particular condition. Importantly, this research has demonstrated to us the circumstances likely to give rise to various complications so that we have been able to develop ways of avoiding problems.

The second form of research is to prepare a 'case report', which is useful for drawing attention to rare conditions and unexpected outcomes after treatment.

### ***Basic science research***

Basic science research is essential for understanding the cause and the behaviour of uveal melanoma. The availability of numerous tumour specimens and blood samples creates special opportunities for making a contribution to current knowledge in this field. Several years ago we decided that if patients had a voice and knew what to ask of us they would encourage us to do more to prevent ocular tumours from recurring in other parts of the body. We have therefore collaborated closely with scientists having special expertise in tumour genes. They have been investigating abnormalities in chromosomes 3, 6 and 8, which influence tumour behaviour. Our research has profoundly influenced our patient care.

The specimens we use for research mostly consist of material left over following diagnosis or treatment and surplus to clinical requirements. Recently, specimens used for research have come to be regarded as gifts so that our institution becomes the 'custodian' of this precious material. The specimens and related data are treated with full confidentiality. The samples are not be used for financial gain. If tissue is not used for research it is either incinerated or stored in case there is ever a clinical need to review the specimen.

Consent for the use of surplus tissues is always obtained from the patient if the results of the research can be linked to the individual and if there is any possibility that such results might affect the patient's interests. When obtaining consent, patients are informed of any physical risks associated with collecting the sample, how the sample will be used, and how the research results might impact their interests. It is considered acceptable to use tissue material surplus to clinical requirements without obtaining the patient's consent if the material was archived before April 2002 and if the sample is anonymous so that it can no longer be linked to the patient. Legislation regarding the use of human tissues for research is updated from time to time.

When a specimen has been used for a particular research project, for which specific consent has been granted, any material left over could still be very useful for new experiments that could not be foreseen when initial consent was first granted. We therefore obtain a second consent for the storage of any surplus material and for future use in other research. However, it is emphasised that even when the research results are linked

with the patient's clinical data such secondary research will not have any direct implications for the donor. Patients are not obliged to give consent for a specific research project or for secondary, unspecified studies. The patient's care will not be altered in any way if consent for research is withheld.

Before starting the study and before obtaining consent, a decision is made as to whether it is in the patients' best interests to be given the opportunity of receiving any feedback about the results of the study. Such feedback may be offered individually or generally by means of a website or newsletter. The summaries of any published articles can be seen by logging onto the Pubmed website [www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed) and typing 'Damato B eye' or 'Coupland SE eye'. This provides a list of articles. Clicking on the authors' names should produce the summary.

### ***International Ocular Oncology Research Societies***

Collaboration between ocular oncologists from different countries creates opportunities for sharing clinical and laboratory data, making it possible to investigate rare situations, which cannot be adequately dealt with by any individual centre. Our centre has actively participated in the European Ocular Oncology Group, the International Society of Ocular Oncology and the European Organization for Research and Treatment of Cancer.

Further information on research guidelines can be obtained at websites of the Medical Research Council, the General Medical Council, the World Medical Association and others (Chapter 22).

## ***Research Achievements***

We have published well over a hundred articles in scientific journals. The main topics are:

### Cause of uveal melanoma

We performed several studies in collaboration with the Institute of Cancer Research, showing that the causes of skin melanoma differ from those of uveal melanoma.

### Detection of uveal melanoma

We have performed the largest study yet undertaken into the detection of uveal melanoma. We have developed novel techniques for detecting hidden blindspots in the field of vision, one of which is available free of charge on the internet (another world first).

### Diagnosis of ocular tumours

We have developed a novel technique for sampling tumours at the back of the eye, using a mini-vacuum cleaner. We have also created a novel internet atlas that allows doctors to diagnose tumours they don't even know exist.

### Pathology of uveal melanomas

We have performed several studies looking into the genetic clockwork of uveal melanomas. We were the first to introduce cytogenetic studies into clinical ocular oncology and therefore have the greatest experience worldwide.

### Staging ocular tumours

We have profoundly influenced the international TNM staging of intraocular and conjunctival melanomas and lymphomas.

### Treatment of ocular melanomas

We have developed or refined several treatments for uveal melanoma, and our techniques are being used worldwide. Our innovations include: (1) developments in

local resection of uveal melanoma ('trapdoor operation' and 'hoovering operation'); (2) treating iris melanomas with proton beam radiotherapy; (3) various modifications of proton beam radiotherapy of uveal melanomas at the back of the eye (e.g. to avoid eyelid damage); (4) treatment of choroidal melanomas with eccentrically positioned radioactive applicator, thereby avoiding loss of vision in many patients and (5) treating 'toxic tumours' after radiotherapy. We have developed a number of surgical tools.

### Personalised prognostication for patients with uveal melanoma

We have developed and validated innovative statistical techniques for estimating the survival probability of individual patients, using clinical, pathological and cytogenetic information. This prognostication enables us to reassure patients with non-lethal uveal melanoma while focussing intensive care at those patients who have a high risk of relapse.

### Treatment of metastatic disease

We are involved in research aimed at improving the detection and treatment of metastases from uveal melanoma.

### Other ocular tumours

We have gained new information on the clinical features and treatment of ocular lymphomas, metastases, vasoproliferative tumours, paraneoplastic syndromes and a variety of tumours other than melanoma and have published our findings.

### Patient care

We have published articles on decision making, recording consultations and other general aspects of patient care. We have also played a major role in developing a questionnaire for measuring quality of life after treatment of an ocular tumour

## Audit

---

Audit is the process whereby clinical and administrative activities are subjected to rigorous quality control studies periodically or continuously so that standards of care are improved.

Clinical topics we investigate include:

- survival;
- conservation of the eye;
- preservation of vision;
- complications;
- quality of life; and
- results from the patient's point of view (ie, 'patient-related outcome measures').

Administrative topics we audit include:

- time between receipt of patient referral and first clinic appointment;
- time between first visit and treatment;
- satisfaction of patients; and
- satisfaction of referring ophthalmologists.

We have a full-time data manager, who ensures that the database is correct and complete.

We have introduced a structured questionnaire for routinely eliciting and recording all ocular symptoms of all patients at every follow-up clinic.

We have also developed a system for recording accidents as well as 'near-misses', so that complications can be prevented.

The audit results are reviewed as soon as they become available.

Appropriate action is taken after discussions are held amongst members from different disciplines at our centre (i.e. multidisciplinary meetings).

The Department of Health has published standards, which must be met by cancer care providers and we assess our own results in terms of these standards.

Our centre is reviewed by peers from other ocular oncology centres in the UK to ensure that a high quality of care is maintained. A peer review in 2006 gave us a glowing report.

We also invite external assessors from other countries once a year. They inspect our service and write a report.

In addition, we provide our funding authority, NSCAG, with our own results upon request so that they can assess our performance.

**Extracts from "The Protection and Use of Patient Information: Guidance from the Department of Health"** (<http://www.doh.gov.uk/ipu/confiden/protect/pguid6.htm>)

We keep information about you...  
...together with details of your care. Everyone working for the NHS has a legal duty to keep information about you confidential. You have a right of access to your health records.

We only ever use or pass on information about you if people have a genuine need for it in your and everyone's interests. Whenever we can we shall remove details which identify you. The sharing of some

types of very sensitive personal information is strictly controlled by law. Anyone who receives information about you is also under a legal duty to keep it confidential.

The main reasons for which your information may be needed are:

- Giving you health care and treatment;
- Looking after the health of the general public;
- Managing and planning the NHS;
- Making sure that our services can meet patient needs in the future;
- Paying staff and the hospital which treats you for the care they provide;
- Auditing accounts;
- Preparing statistics on NHS performance and activity;
- Investigating complaints and legal claims;
- Helping staff to review the care they provide to make sure it is of the highest standard;

- Training and educating staff (but you can choose whether or not to be involved personally);
- Research approved by the Local Research Ethics Committee. (If anything to do with the research would involve you personally, you will be contacted to see if you are willing to take part. You will not be identified in any published results without your agreement.)

If you agree your relatives, friends and carers will be kept up to date with the progress of your treatment.

If at any time you would like to know more about how we use your information, you can speak to the consultant ocular oncologist or the specialist ocular oncology nurse.

## Teaching

---

### *Trainees*

It is the duty of our consultants to teach junior colleagues as much as possible about the care of patients with ocular melanoma and other tumours.

Trainees learn by examining patients in the clinics and the wards, contributing to patient care, discussing clinical problems and findings with the consultant, and assisting at surgery. They also gain valuable experience by performing certain surgical procedures and laser treatments themselves, with appropriate guidance and supervision and only when it is safe and useful for them to do so. As a rule, a consultant performs much of the surgery, because of the specialised and difficult nature of this work.

### *Visitors*

Each year, we receive several ophthalmologists from overseas with a special interest in ocular tumours. They come to see how our centre is organized and how we manage our patients.

Visitors usually stay only for one or two weeks. Most visitors are either distinguished ocular oncologists or trainees working with such persons.

Strict safeguards ensure that no problems arise as a result of a visit by a doctor from another hospital. Each visitor is required to submit a curriculum vitae so that we can get official permission from the Medical Director of the Royal Liverpool University Hospital for the visit to take place.

Most visitors come as observers and are not allowed to perform any treatment or

surgery. If a visitor wishes to get involved in patient care and to perform surgery, then a contract is drawn up with our hospital. Such a contract is granted only once original professional certificates have been scrutinized by the personnel officer and once the visitor has passed a health check.

Visits to our centre by overseas specialists bring several benefits. Firstly, they keep us all on our toes, asking probing questions and commenting on our methods. Secondly, they invariably give us valuable feedback on our results and on anything they find surprising or unusual. This is almost always positive criticism, and coming from an expert is most reassuring and encouraging. Thirdly, it is gratifying for us when we meet them at international conferences months or years later and when they tell us what changes they have made to their own centre after their visit to our department. There are one or two difficulties that can arise. For example, their presence can slow down a busy clinic if one is not too careful, although various discreet ways of not letting this happen have been developed.

### *Lectures*

Lecturing is an important part of the consultant's programme, consisting of one or two lectures a month, nearly always quite far away from Liverpool and usually overseas. On most occasions, we are invited to give these lectures because ocular oncologists are few and far between and general ophthalmologists are very keen to keep up to date, even if they only see one or two patients with an ocular tumour each year.

The meetings include:

- Departmental conferences attended by all the staff of a particular eye unit;
- Regional meetings held by ophthalmologists in a particular part of the country;
- National annual conferences, attended by hundreds of ophthalmologists from all over that country; and
- International congresses, attended by thousands of delegates from all over the world.

Conferences are hard work and tiring in some respects but provide a refreshing break from routine and there is nearly always an important lesson or idea to bring back home.



**The International Conference Centre, Kyoto**

### ***Publications***

#### ***Scientific Articles***

The most satisfactory outcome of any research project is the publication of any findings in a scientific journal.



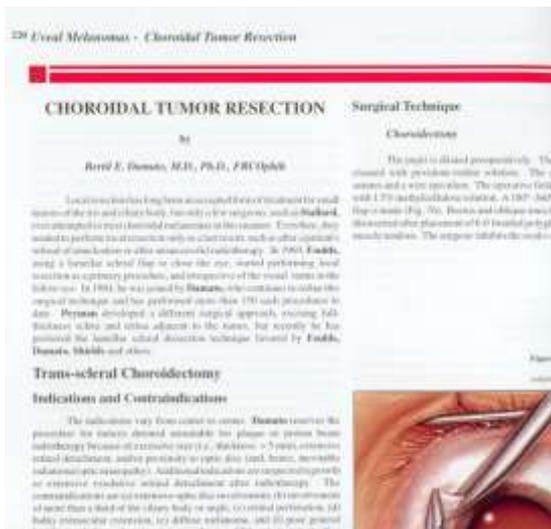
**Scientific articles published on outcomes after treatment of ocular melanoma**

When an article is submitted for publication, it is subjected to peer review by two or three acknowledged experts in the field. They prepare an anonymous critique of the article, recommending to the editor whether the article should be accepted, rejected, or re-considered after corrections have been made.

Whenever a scientific article appears, the title, the authors' names and addresses, and the abstract are published in an electronic index, which can be reviewed on the internet and in any hospital or university library. In this way, other workers around the world will know about the article and can read the publication.

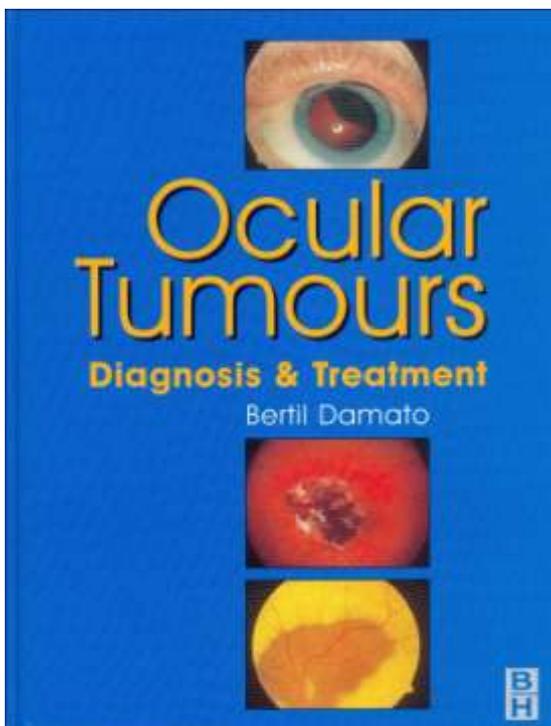
#### ***Textbooks***

Despite our electronic age, textbooks are still an important source of information. They are mostly written by numerous authors, each author writing one or two chapters. They are invited to contribute these chapters to the textbook by an editor, who is in charge of the selecting contributors and checking the work submitted.



**Chapter on local resection in Boyd's textbook on ophthalmic surgery**

Single author texts are still published, in which an authority in a special field covers the entire subject alone or with one or two co-authors.



**Textbook aimed at general ophthalmologists, optometrists and other practitioners involved in the care of patients with ocular tumours**

**Electronic Media**

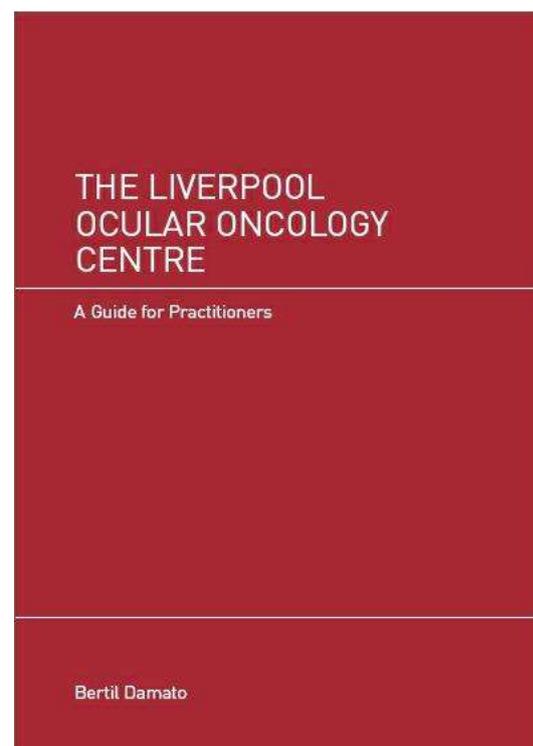
Increasingly, scientific texts are being published on CD roms and on the Internet

so that they are more widely available and more easily 'searchable' using key words. Much of this information is accessible to the lay public.

In 2002, Professor Damato prepared a 'virtual lecture' on ocular tumours, which was circulated on CD-ROM to over 8000 optometrists by the College of Optometrists. This was so successful that a few years later he was invited to prepare a second virtual lecture, which was circulated to around 10,000 optometrists, both on CD-ROM and on the internet. This teaching should greatly enhance optometrists' awareness of ocular tumours, increasing any chances of early detection and treatment.

**Guide for Practitioners**

In 2006, we published a Guide for Practitioners, which was distributed free of charge to all ophthalmologists who have referred patients to our service within the previous three years. We hope to do this again soon.



**Guide distributed to referring ophthalmologists, to enhance patients' care at their local hospital**

The objectives of this 70-page guidebook are to advise ophthalmologists how to refer patients safely and how to collaborate with us in the patient's long-term after-care. The publication of this book was funded entirely by our **Eye Tumour Research Fund**.

### *Video Communications*

Most video communications tend to show extracts of surgical operations and are designed to demonstrate a new technique or a method of avoiding or dealing with complications. These videos are usually shown at conferences, either as part of an oral lecture, or in a special hall, where videos from numerous contributors are shown continuously. With the development of digital video, it is technically possible for animated images to be included in teaching websites on the Internet.

We have recently started obtaining consent for video recordings of surgical procedures, whether or not the patient is identifiable. If asked for such consent, you are under no obligation to give your permission for the recording to be made and your decision will not influence your

care in any way. Current GMC guidelines suggest that patients should be given the chance, if they wish, to see the recording in the form in which it will be shown. However, as with any surgical video, the images may be upsetting for a non-medical person.

### *Posters*

Almost all conferences now include poster displays, with each poster summarising a study or case presentation, with graphs and photographs as necessary. Poster sessions are usually organized so that the authors will stand next to their exhibits at selected times, so that they are available to discuss their work with other delegates. This is a highly effective form of communication because it allows a one-to-one discussion with the author of the work.

In all scientific communications, special precautions are taken to ensure that the patient's confidentiality is respected at all times. Patients' names and hospital numbers are obscured and if it necessary to show a photograph of a face, then specific consent is obtained from the patient.

## Keeping up to date

We keep up to date by reading journals and textbooks, either in a library or using our personal collections, which we have built up at our own expense.

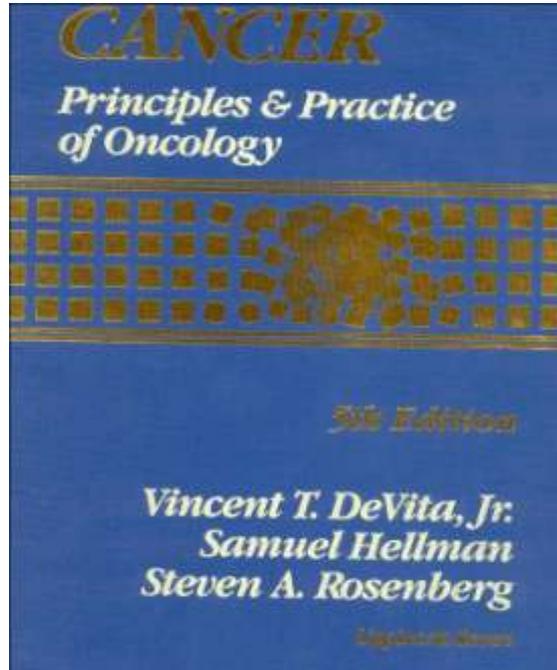


**Some important scientific journals**

We also scan electronic libraries on the Internet. These sites automatically inform us of any new articles relevant to our specialist field.



**An electronic library**  
(<http://www.ncbi.nlm.nih.gov/entrez>)



**A standard text on cancer**

Attendance at scientific conferences is an effective method of learning, not only because we can obtain information before it has even been published in the journals but also because we meet the researchers themselves so that we can have in-depth discussions.

Case reports and anecdotes are particularly instructive because they enable us to be prepared to deal with rare conditions we may not have encountered previously.

# Miscellaneous Topics

## How you can help

---

### *By understanding your condition*

An important way in which you can help us is to understand as much as you can about your condition, reading any material that is provided and feeling free to ask questions. We believe that patients who are well informed about their tumour tend to worry less about their condition and generally cope better than those who leave too much to their own imagination.

### *By giving us feedback*

Feedback is very important and it would be very helpful if you could complete and return any questionnaires that you receive. There are two types of questionnaire. The first, dealing with patient satisfaction, will ask you questions about administrative matters, your experience in hospital and how you feel about the results of your treatment. The second type of questionnaire measures various aspects of your quality of life so that we can assess our treatments and advise future patients how they might feel and how any psychological difficulties might be addressed.

### *By complaining*

If there is anything you are unhappy about, you are encouraged to make a complaint, which will help us rectify the problem.

### *By donating tissue and blood samples for research*

It would be very helpful indeed if you could give us consent to use tissue and blood samples for research. In addition, we would like to use your clinical data for outcomes evaluation and photographs for teaching and research purposes. As mentioned previously, your anonymity

and confidentiality will be protected. National and international regulations ensure that no harm whatsoever will come from using your data, images or tissues for research, teaching or audit.

### *By speaking to new patients about your own experience*

Another way in which you can help is to volunteer to speak to new patients to give them some idea of your own experiences, both good and bad. Depending on your preference, we can either give them your telephone number or we can telephone you with their number. If you agree, it is likely that you will be asked to speak to one or two new patients each year.

### *By making a financial donation*

Many patients have donated money to the **Eye Tumour Research Fund** and this assistance is extremely valuable. Some patients have made a personal contribution and others have collected money from sponsored walks, tea-parties and other enjoyable events. Some patients have left lasting bequests in a will. Such legacies and other contributions have enabled us to develop our database, to purchase computers and software programs for teaching and research, to attend congresses (travelling economy class), to purchase a wide-angle camera, and to start off research projects. We also use this fund to contribute towards the salaries of research scientists.

**The Eye Tumour Research Fund** is a recognised charitable fund managed by the Royal Liverpool University Hospital, which oversees the fund and which needs to grant its permission before any money can be spent.

Donations can be made in the following manner:

- By handing in your donation at the general office of the hospital, which is on the first floor.
- By writing a cheque payable to '***The RL&BUH Trust Funds-Eye Tumour Research Fund***' and posting this cheque to the General Office, Royal Liverpool University Hospital, Prescot Street, Liverpool L7 8XP.
- By speaking to a will writer or solicitor

If you pay income tax you can claim tax relief on your contributions. All you have to do is to write an accompanying letter with the words 'Gift Aid Declaration: I am a UK tax payer and would like the RL&BUH Eye Tumour Research Fund to reclaim tax on all contributions I make from this declaration until I notify otherwise'. This letter should be signed and dated and should also have your full name and address. Further information about gift aid declarations can be obtained by asking us or your local tax office for leaflet IR 113 *Gift Aid*.

Please inform the ocular oncology consultant, specialist nurse or secretary if you make a donation. If you wish to make any enquiries about making a donation, please phone the specialist nurse at 0151 706 3976. You can also contact:  
The Charitable Funds Section,  
1<sup>st</sup> Floor, Pembroke House  
Royal Liverpool University Hospital  
Prescot St, Liverpool, L7 8XP  
Tel: 0151 706 2000 (ext 2833 or 2834)  
You will receive a receipt from the hospital.

### ***By attending our patient focus group meetings***

About once a year, we hold a patient focus group meeting on a Thursday morning so that patients attending our follow-up clinic can speak about their experiences and make suggestions for improvements. Minutes of the meeting are discussed by members of our centre.

### ***By giving us advice and feedback***

We rely on our patients to:

- Discuss with us how various aspects of care might be improved;
- Assess any newsletters, guides, information sheets, or other literature we may have prepared, before large scale distribution to patients, to check that such material is interesting, relevant, correct, and easily understood;
- Discuss with us our various clinical and research activities, so as to ensure that everything we do is fully in accord with our patients' wishes and attitudes;
- Join us in our campaign for improved resources, when we negotiate with health authorities for more funds and better access to modern tests and treatments;
- Provide a voice for 'consumer-driven' progress.

Please look out for invitations in our clinics, on our website, or in any correspondence or newsletters you receive - or simply volunteer, by phoning or writing to us or by speaking to a member of our team when you attend our hospital.

## The Patient's Charter

---

This chapter contains relevant extracts from the Patient's Charter for England, with a few minor amendments where appropriate.

You have the right to:

- Receive health care on the basis of your clinical need, not your ability to pay, your lifestyle or any other factor;
- Be referred to a consultant acceptable to you, when your GP thinks it is necessary, and to be referred for a second opinion if you and your GP think this is desirable;
- Choose whether or not you want to take part in medical research or medical student training;
- Have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to you before you decide whether to agree to it;
- Have access to your health records, and to know that everyone working for the NHS is under a legal duty to keep your records confidential;
- Have any complaint about NHS services (whoever provides them) investigated to get a quick, full written reply from the relevant chief executive or general manager. The new complaints procedure means this will be within four weeks;
- Receive detailed information on services. This includes information on the standards of service you can expect and waiting times;
- To be told before you go into hospital whether it is planned to

care for you in a ward for men and women;

You can expect:

- The NHS to make it easy for everyone to use its services, including children, elderly people or people with physical or mental disabilities;
- All the staff you meet face to face to wear name badges;
- The NHS to respect your privacy, dignity and religious and cultural beliefs at all times and in all places. For example, meals should suit your dietary and religious needs. Staff should ask you whether you want to be called by your first or last name and respect your preference;
- Your operation not to be cancelled on the day you are due to go into hospital or after you have gone in. If it is, (for example because the hospital is dealing with the victims of a major road traffic accident), you can expect to be admitted again within one month of the cancellation;
- To be given a specific appointment time and be seen within 30 minutes of that time;
- Your relatives and friends to be kept up to date with the progress of your treatment, if you agree;
- Single sex washing and toilet facilities;
- To be given a written explanation of the hospital's patient food, nutrition and health policy and the catering services and standards you can expect during your stay;

- To have a choice of dishes, including meals suitable for all dietary needs;
- To have to order no more than your next two meals in advance;
- To have a choice of the size of portion you want;
- To be the name of the catering manager;
- To have help, if you need it, to use the catering services; for example, menus printed in other languages and large print. This help should be readily available.
- Enquiry points and clear signposting to help you and your visitors to find your way around;
- To be cared for in an environment which is clean and safe;
- Reasonable measures to be taken for your personal protection and safety;
- To have facilities to keep personal money and belongings safe;
- A decision to be made, before you are discharged from hospital, on how to meet any needs you may continue to have. Your hospital will agree arrangements with agencies such as community nursing services and local

authority social services departments. You and, if you agree, your carers will be involved in making these decisions and kept up to date with information at all stages;

- Waiting times for taking you home after you have been treated if your doctor says you have a medical need for NHS transport;
- Your hospital to display information on the Patient's Charter including local standards and whether they are meeting them;
- Your hospital to make it clear how you can complain or make comments and suggestions while you are in hospital;
- Your hospital to publish regularly details of the number of complaints they have received and the time they took to deal with them.

## How to make a complaint

---

Complaints are useful because they enable us to identify and rectify problems, making our hospital better and safer. There are several ways in which you can make a complaint.

### ***By speaking to a member of staff***

You can voice your complaint about a problem to any member of staff. Alternatively, you can contact the Customer Relations Team (CRT):

Elaine Rattigan, Customer Relations Team  
Tel 0151 706 4903

**Bleep: 4273**

**E-mail: [elaine.rattigan@rlbuht.nhs.uk](mailto:elaine.rattigan@rlbuht.nhs.uk)**

If you mention a problem to our specialist ocular oncology nurse or consultant, a letter will be written to the relevant authority. A copy of this letter will be filed. When a response is received, we will inform you of this response.

### ***By writing a letter to the Chief Executive of our hospital***

If you are not satisfied with the response to an informal complaint or if you wish to make a more formal approach, you can write to: The Chief Executive, Royal Liverpool and Broadgreen University Hospitals NHS Trust, Prescot Street, Liverpool L7 8XP

### ***By speaking to the Director of Quality***

If you are unable to complain in writing or if you wish to speak in person, please contact:

**Denise Carroll**

Directorate of Clinical Governance and Quality (0151 706 2251)

**[Denise.carroll@rlbuht.nhs.uk](mailto:Denise.carroll@rlbuht.nhs.uk)**

This official will take the relevant details and investigate the matter. You will be contacted immediately if possible, but certainly within three working days, in order to agree an appropriate action plan to determine how the complaint will be handled. At this point a timeframe for responding to the issues raised will be agreed and recorded in the Management Plan.

### ***By requesting an investigation by an independent review panel***

If you are dissatisfied with a response to your complaint, you can write to the Chief Executive, requesting an investigation by an independent review panel. You must do this within 20 working days. A representative will contact you to ask why you are dissatisfied and will decide whether a panel can resolve the problem.

If the independent review panel investigates your complaint, the Chief Executive will write to you to inform you of the panel's conclusions. This process can take up to six months.

### ***By writing to the Health Service Ombudsman for England***

If your complaint is not considered by the independent review panel or if you are dissatisfied with the conclusions reached by that panel, you can appeal in writing to:

The Health Service Ombudsman for England, 11<sup>th</sup> Floor, Millbank Tower  
Millbank, London, SW1P 4QP.

The health service ombudsman's services are free and completely independent of the government and health authorities.

## Who's who

### **Anaesthetist**

The anaesthetist is a medically qualified doctor specializing in the prevention of pain.

### **Basic Scientist**

Basic scientists perform laboratory research, in fields such as molecular biology, cell biology, genetics, and pathology.

### **Buddies**

Buddies help patients in many ways. They shop for essentials like milk and bread on the patient's way home and then settle the patient in their home.

Buddies also bring nervous patients to hospital and keep them company. This is an important service for patients who have no family and feel vulnerable. Buddies will also collect pensions or personal items from a patient's home if they have no family at hand. They will also escort in-patients who wish to visit their home, go to the bank, visit their pets in kennels etc. and will generally be there for moral support. To patients who have no relatives or friends close by, this can make a huge difference to their recovery and confidence.

### **Business Administrators**

A team of administrators run the unit, performing the following tasks:

- Communicating with the Department of Health regarding all administrative aspects of the centre;
- Liaising with the ocular oncologist on all financial matters related to

the development of the oncology centre;

- Organizing the purchase of equipment;
- Organizing systems for accommodating patients and relatives, providing interpreters, and handling private fees.
- Running inpatient and outpatient services at St Paul's Eye Unit.

### **Clerical Officer**

The ocular oncology clerk has the following duties:

- Reception duties in outpatient clinics;
- Preparing casenotes;
- Obtaining the fax numbers of referring ophthalmologists and general practitioners;
- Retrieving and archiving casenotes and photographs for outpatient clinics, audits and research projects;
- Booking and cancelling clinic appointments; and
- Digitising casenotes on computer when patients are discharged from our service.

### **Clinical director**

The clinical director is responsible for the running of St Paul's Eye Unit. He or she is normally appointed from the consultant team for a period of three years.

### **Compliance Officer**

The compliance officer ensures that we in the oncology service all comply with:

- The patients' wishes and preferences, particularly with regards to consent for the use of data, images and tissues for research, teaching and audit. Permission is also obtained for quality

of life quality of life questionnaires and newsletters.

- All conditions imposed by organizations such as the Liverpool Research Ethics Committee, the Trusts Research and Development department, the Medical Healthcare Regulatory Authority. We also follow the research guidelines issued by the International Conference of Harmonisation for Good Clinical Practice.

### ***Consultant ocular oncologist***

The consultant ocular oncologist is an ophthalmologist specializing in the diagnosis and treatment of ocular tumours. We now have two consultant ocular oncologists, one working full-time in ocular oncology and the other working also in medical and surgical retina.

### ***Cytogeneticist***

The cytogeneticist examines tumour tissue to identify genetic abnormalities arising in the tumour. These studies indicate whether or not a melanoma is likely to behave aggressively.

### ***Data manager***

The data manager ensures that our ocular oncology database is complete, correct and up-to-date. The duties of the data manager include:

- Checking the notes every time a patient is seen, to ensure that there are no errors in the database;
- Computerizing data returned by referring ophthalmologists and in questionnaires;
- Computerizing information received from the National Cancer Registry;
- Retrieving the NHS number of each new patient from the general practitioner or the referring health authority;
- Performing various studies, such as the quarterly review of activity; and

- Providing assistance when our usual oncology secretary is absent.

### ***Health Psychologist***

The health psychologist:

- Identifies any psychological problems in patients and accompanying persons;
- Organizes any psychological support, if requested by the patient, liaising with the family doctor or with other practitioners, as required;
- Conducts quality of life studies and research into patients' psychological needs;
- Provides psychological support by means of printed leaflets and the ocular oncology website;
- Advises the ocular oncology staff on psychological aspects of patient care.

In the UK, chartered health psychologists obtain an undergraduate psychology degree followed by a postgraduate qualification in health psychology. They then practise health psychology under supervision for at least two years.

### ***Medical Ethicist***

The medical ethicist has qualifications in Health Care Ethics and helps to resolve any dilemmas relating to treatment or research. For example, he provides advice on new treatments and investigations to ensure that any novel care provided is always in the best interest of the patient.

### ***Medical oncologist***

The medical oncologist is a doctor specializing in the treatment of cancer by chemotherapy or immunotherapy.

### ***Nurse***

The primary route to obtaining a nursing qualification in England is the Diploma of Higher Education in Nursing. This is of three years duration.

Graduates holding a health-related degree can follow an accelerated diploma programme.

Nurses wishing to work in ophthalmology need to complete a course in ophthalmic nursing, which is a part-time, modular course lasting 42 weeks.

Ophthalmic nurses can also obtain a specialist ophthalmic practitioner qualification, leading to a BA (Hons) in health care practice.

### ***Ocular Oncology Fellow***

The ocular oncology fellow is an ophthalmologist who is already trained in general ophthalmology and who is obtaining specialized experience in ocular oncology.

### ***Ocular oncology secretary***

The ocular oncology secretary is responsible for all administrative matters related to our centre. The duties involve:

- Handling all correspondence;
- Typing and filing all letters;
- Organizing clinics and admissions;
- Arranging accommodation for patients and relatives;
- Organizing an interpreter, if required for an overseas patient;
- Preparing operating theatre lists;
- Organizing fax and telephone communications between our centre and radiotherapists at the Clatterbridge Centre for Oncology;
- Preparing and circulating questionnaires.

### ***Photographer***

Ophthalmic photographers specialize in taking colour photographs and angiograms of the eye, using special equipment.

### ***Pathologist***

The pathologist is a doctor specializing in pathology, which is the study of disease. This involves:

- Measuring and describing all specimens, both macroscopically (i.e., using the naked eye) and with a microscope;
- Providing a diagnosis;
- Reporting any tumour characteristics of prognostic value;
- Preparing a dictated report, for filing in the case notes, a copy of which is routinely sent to the referring ophthalmologist;
- Archiving tumours and any tissues that have been removed, in case any analysis is required and for research. This is done in accordance with Ethical Committee guidelines.
- Completing a proforma, for computerization of relevant data;
- Organizing regular clinico-pathological multidisciplinary team meetings, so that tumour specimens can be discussed in detail with the surgeons;
- Participating in teaching and research.

### ***Radiologist***

The radiologist is a doctor specializing in body imaging, that is, x-rays, magnetic resonance imaging, and computerized tomography.

### ***Radiotherapist***

The radiotherapist is a doctor specializing in radiotherapy, which is the treatment of tumours with radiation.

### ***Surgical trainee***

The duties of surgical trainees involve:

- Examining patients on admission to hospital and preparing patients for surgery;
- Organizing any relevant tests and retrieving the results;
- Assisting at theatre and in the clinics; and
- Contributing to patient care in the ward.

At the end of their training, surgical trainees need to pass an exit examination to be able to compete for a post as consultant ophthalmologist. Trainees rotate through all sub-specialties in ophthalmology, including ocular oncology, spending between three and six months in each firm.

### ***Specialist ocular oncology nurse***

The specialist ocular oncology nurse is an ophthalmic nurse who dedicates the whole of her time to the care of patients with ocular tumours. The duties involve:

- Counselling patients in the clinic and the ward;
- Providing a telephone help-line;
- Assisting with patient satisfaction studies and other projects;
- Assisting the consultant at clinics and in the operating theatre; and

- Running some outpatient clinics.

The specialist ocular oncology nurse is designated as your 'Key Worker', which means that she is responsible for dealing with any problems that you might have.

### ***Vitreoretinal surgeon***

The vitreoretinal surgeon is a consultant ophthalmologist who specializes in the surgical treatment of retinal disorders.

### ***Medical Retina Consultant***

The medical retina consultant specializes in the treatment of retinal disorders such as vascular tumours (i.e., blood vessel tumours) and retinal oedema (i.e. fluid in retina). This is using lasers and ultraocular injections of steroids and other agents.

# 19

---

## Directory

### LIVERPOOL OCULAR ONCOLOGY CENTRE

#### *Consultant/Clinical Lead*

Professor Bertil Damato

Tel: 0151 706 3973

Fax: 0151 706 5436

#### *Day Case Theatre*

Tel: 0151 706 3936

#### *Operating theatre*

Tel: 0151 706 2000 (ext: 3942)

#### *Outpatient clinic*

Tel: 0151 706 3870.

#### *Buddies Service*

Tel: 0151 706 3170.

Email: [Doreen.Ryan@rlbuht.nhs.uk](mailto:Doreen.Ryan@rlbuht.nhs.uk)

#### *Secretary*

Tel: 0151 706 3973

Fax: 0151 706 5436

E-mail: [Julie.Sudlow@rlbuht.nhs.uk](mailto:Julie.Sudlow@rlbuht.nhs.uk)

#### *Specialist oncology nurses*

Tel: 0151 706 3976

E-mail: [Gillian.hebbar@rlbuht.nhs.uk](mailto:Gillian.hebbar@rlbuht.nhs.uk)

E-mail: [jean.hannah@rlbuht.nhs.uk](mailto:jean.hannah@rlbuht.nhs.uk)

#### *Health Psychologist*

0151 706 3127

#### *Ward 9Y*

Tel: 0151 706 2000 (ext: 2496)

---

### CLATTERBRIDGE CENTRE FOR ONCOLOGY

Tel: 0151 334 6366

Please ask the telephone operator for the senior proton radiographer or the cyclotron secretary.

---

### ROYAL LIVERPOOL UNIVERSITY HOSPITAL

#### *Main switchboard*

Tel: 0151 706 2000

#### *Catering Manager*

Extension: 2010

## Hospital Facilities

---

### *Hospital chaplain*

A hospital chaplain of your selected denomination will visit you if you wish. Just ask a nurse, who will pass on your request.

Religious services for various denominations are held in the hospital chapel.



**The chapel**

### *Postbox*

A postbox is present next to the main entrance.

### *Tea Bar*

The WRVS operates a tea bar in the outpatient department on the ground floor from 9.00 am to 4.00 pm each weekday. A trolley service is also provided to clinics. There is also a café on the mezzanine.

### *Telephone*

Public telephones are available:

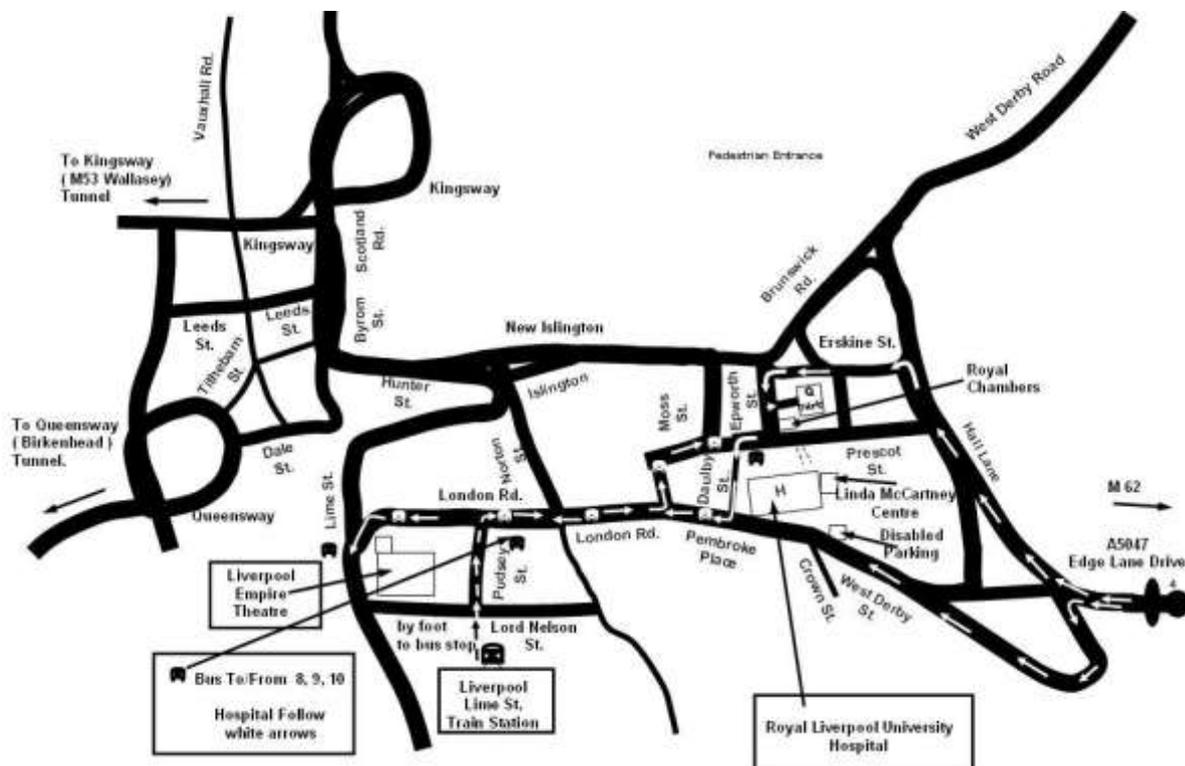
- in the main entrance hall;
- outside the ward;
- adjacent to all hospital beds.

### *Television*

Most beds are now equipped a personal TV.

## How to get there

### Royal Liverpool University Hospital



#### *Liverpool*

##### By plane

Manchester airport is one of the largest airports in the UK with many international connections. It is located about 36 miles from Liverpool. A taxi journey between Manchester airport and Liverpool normally takes 45 minutes as costs about £50, reduced to approximately £45 if the taxi is pre-arranged.

Liverpool Speke airport is about 5 miles from the city centre. You can travel to the city centre by taxi in about 20 minutes, at a cost of approximately £20.

##### By train

The train station closest to the hospital is Lime Street Station. A taxi from the station to the hospital would cost about £5.00.

#### *The Royal Liverpool University Hospital*

##### By car

From M62, drive straight along Edge Lane. If you wish to park your car in the patient's multistorey car park in front of the hospital, follow the signs prompting you to turn right into

Hall Street. At the next set of traffic lights, do not turn left into Prescott St but drive straight across into Erskine St (A580), keeping in the left-hand lane and following the bend to the left. After about 200 metres, follow the sign indicating the Royal Liverpool University Hospital and turn left into the second street (Epworth St), just before you reach the next set of traffic lights.

From M53, drive through the Kingsway Wallasey Tunnel. As you exit, drive in the middle lane and follow the signs to the city centre. Continue through the first set of lights, staying in the left-hand lane and at the next set of traffic lights turn left up the hill. Pass straight through the next two sets of traffic lights onto New Islington. After passing through the next set of lights, move to the right-hand lane and follow the road as it curves 180° to the right. After about 200 metres, turn left into Epworth St, following the sign indicating the Royal Liverpool University Hospital.

#### By bus

The following buses from Queens Square stop at the main entrance in Prescott Street:  
8, 9, 9d, 10, 10a, 10b, and 10c.

The following buses from Queens Square stop at Daulby Street, about 200 metres from the main entrance:  
4 and 4b.



**Main entrance to hospital**

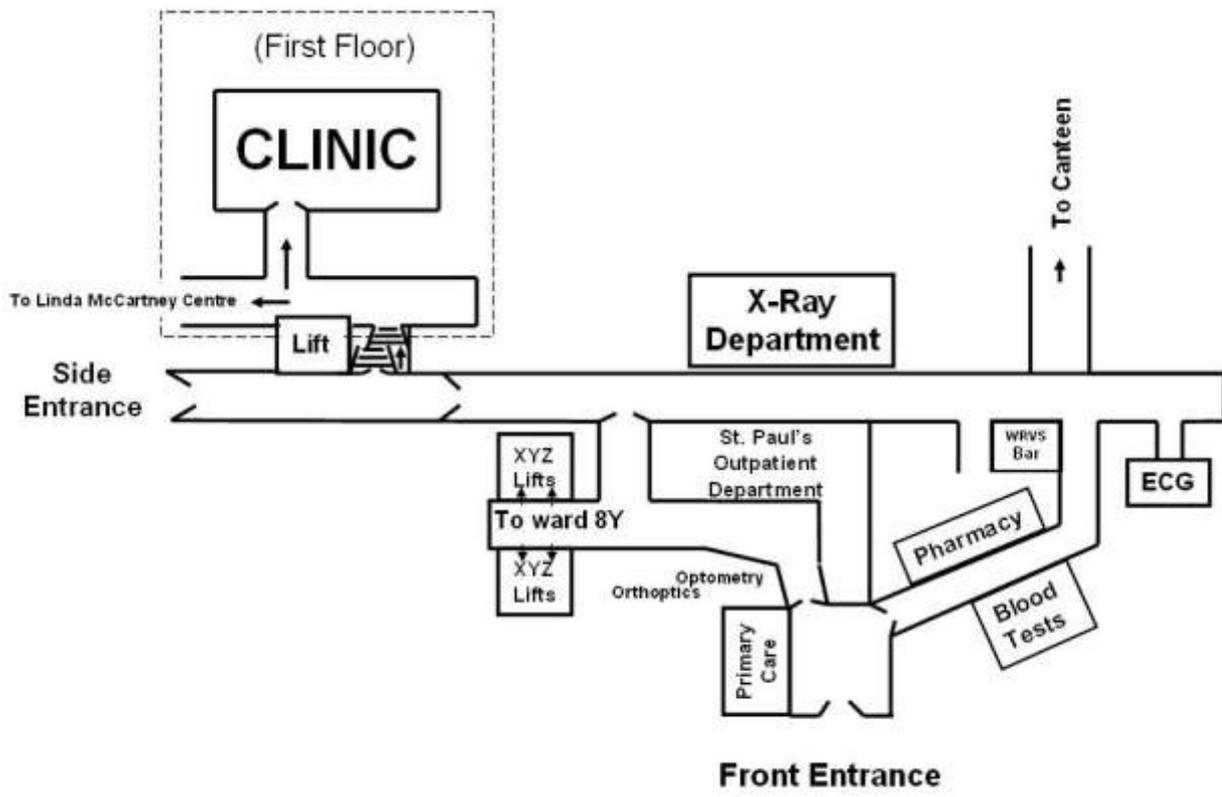
#### ***Royal Chambers***

If you introduce yourself to the security officer at the security office at the main entrance to the hospital you will be taken to the Royal Chambers on Prescott St and shown how to use all the facilities. This accommodation is available only if pre-booked by Mrs Julie Sudlow, Ocular Oncology Secretary.

***The outpatient clinic***  
From the main entrance



If you enter the main entrance you will find yourself in the large entrance hall. The ophthalmic outpatient clinic is reached by a corridor at the far left corner of the main entrance hall as shown in the map below.





**Lift and stairs to Specialist Eye Research Centre, approached from main entrance**

From the side entrance



**Side entrance to hospital**

To reach the outpatient clinic from the side entrance, enter the first door on the left, walk up one flight of steps, turn left and you will see the clinic entrance on the right side of the

corridor. Alternatively, you can take a lift and you will see the clinic entrance directly in front of you as the lift door opens.



**Entrance to Specialist Eye Research Centre**

### ***The day ward***

The entrance to the day ward is directly opposite the entrance to the stairs to the Specialist Eye Research Centre, on the ground floor.

## **Clatterbridge Centre for Oncology**

Full Address:  
Douglas Cyclotron Unit  
Clatterbridge Centre for Oncology  
Clatterbridge Rd  
Bebington  
Wirral  
CH63 4JY

Clatterbridge Centre for Oncology is located on the Wirral Peninsula, very close to Junction 4 on the M53 motorway. Further details will be provided, if necessary, at the appropriate time. A map indicating the location of Clatterbridge Centre for Oncology is shown on the back cover of this guide.

## Liverpool and surroundings



Liverpool has recently seen wonderful re-development. Attractions include the Museum of Liverpool, Tate Gallery, Merseyside Maritime Museum, Liverpool Walker Art Gallery, The Philharmonic Hall. There is also the new shopping centre, Liverpool ONE. Not to mention...The Beatles, football, the Yellow Duckmarine and much more.

### *Albert Dock*

In the late 19<sup>th</sup> century, this was the gateway to the United States. It was recently restored into a complex of shops, restaurants, and museums.



**Albert Dock**

### *Anglican Cathedral*

A magnificent gothic cathedral started in 1904 and completed in 1978. Designed by Sir Giles Gilbert Scott, who also designed the old, red telephone box. This is the largest cathedral in Britain and has the largest organ in the world. Be sure to walk behind the altar and visit the Lady Chapel. The café is very popular with locals.



**The Anglican Cathedral**

### *Beatles Tour*

A bus tour of places related to the famous pop group, the Beatles, provides a good way of seeing the city.

### ***Chester***

This is a beautiful walled city, with the famous medieval and Victorian, two-tier shopping arcades and the cathedral. About an hour away from Liverpool, conveniently reached by train or car.



**Chester at dusk**

### ***Geography***

Liverpool is virtually at the geographic centre of the British Isles, on the North West coast of Britain, north of the Mersey estuary in the county of Merseyside.

Located 351 miles from Aberdeen, 103 miles from Birmingham, 184 miles from Bristol, 169 miles from Cardiff, 120 miles from Coventry, 282 miles from Dundee, 223 miles from Edinburgh, 225 miles from Glasgow, 77 miles from Leeds, 122 miles from Leicester, 220 miles from London, 36 miles from Manchester, 169 miles from Newcastle, 110 miles from Nottingham, 255 miles from Portsmouth, 237 miles from Southampton, and 171 miles from Swansea,

### ***History***

Liverpool flourished in the 17<sup>th</sup> and 18<sup>th</sup> centuries when trade in sugar, cotton and slaves was at its peak. In the 19<sup>th</sup> century, it was the main port for emigrants to the United States of America. Shipbuilding also developed. Liverpool declined when a large canal was built connecting Manchester to the sea. It was severely bombed during the Second World War. When the two Mersey tunnels were built, in 1934 and 1971 respectively, many

people moved to live on the Wirral peninsula.

### ***Metropolitan cathedral***

This is a modern Roman Catholic cathedral, with a marble altar at the centre of a large circular nave, from which 13 small chapels radiate. The stained glass windows are impressive.



**The Metropolitan Cathedral**

### ***Philharmonic Hall***

Home of the famous Liverpool Philharmonic Orchestra. It was built in the mid 19<sup>th</sup> century, rebuilt after a fire in 1933 and extensively restored a few years ago. The Philharmonic pub across the street is quite spectacular.

### ***Population of Liverpool***

497,000

### ***Port Sunlight***

Located on the Wirral peninsula, this is a beautiful, 130 acre, Victorian garden village built by William Hesketh Lever in 1888 for the workers of his soap factory. It contains the Lady Lever Art Gallery, with its outstanding collection of paintings, statues and furniture.

### ***Rodney Street***

A fine street lined by Georgian houses, including the birthplace of William Gladstone, a former prime minister. The 'Harley Street' of Liverpool, with several private clinics.



**Rodney Street**

***Royal Liver Building***

This famous landmark by the sea has twin towers topped by statues of Liver Birds, from which the city is said to have taken its name. This building also has Britain's largest clock.



**The Royal Liver Building**

***Speke Hall***

A beautiful half-timbered building, one of the best preserved in Britain, built between 1490 and 1612.

***St George's Hall***

This is an imposing Greco-Roman building on Lime Street, finished in 1854.

***Tate Gallery***

This is located in the Albert Dock and houses a part of the National Collection of 20<sup>th</sup> Century Art.

***Walker Art Gallery***

This houses a collection of famous paintings, including works by Rembrandt, Rubens, and George Stubbs, who was born in Liverpool in 1726.

***The Yellow Duckmarine***

The Duckmarine is an amphibious craft, which will take you around the streets of Liverpool and through the docks. The Duck Tour is a pleasant way to see Liverpool, from land and sea.



**The Duckmarine**



**The Liverpool Hilton**

## Useful contacts

---

### INTERNET ADDRESSES

#### *Liverpool Ocular Oncology Centre*

Our own website, created by a grateful patient.

<http://www.eyetumour.com>

#### *Automobile Association*

This site has a free route planner. All you need to do is to enter your postcode and the postcode of the Royal Liverpool University Hospital (L7 8XP) and a personalized map will be provided.

<http://www.theaa.co.uk>

#### *Cancerhelp*

A website for patients, with good advice on coping with cancer.

<http://cancerhelp.cancerresearchuk.org>

This site has a list of government benefits that cancer patients and survivors can receive (e.g., free NHS prescriptions, etc):

<http://cancerhelp.cancerresearchuk.org/coping-with-cancer/coping-practically/financial-support/government-benefits>

#### *Changing Faces*

A website offering information and support to people who are concerned about facial disfigurement

[www.changingfaces.org.uk](http://www.changingfaces.org.uk)

#### *Citizens Advice Bureau*

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

#### *College of Optometrists*

This website describes the role of optometrists. The section entitled Guidance describes how optometrists should examine and refer patients.

<http://www.college-optometrists.org/>

#### *Disabled Living Foundation*

[www.dlf.org.uk](http://www.dlf.org.uk)

#### *Drivers Medical Group*

DVLA Swansea

SA99 1TU

Tel: 0870 600 0301

[www.direct.gov.uk/en/Motoring/index.htm](http://www.direct.gov.uk/en/Motoring/index.htm)

#### *Equality and Human Rights Commission*

[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

#### *Eye Cancer*

A website created by Dr Paul Finger, an ocular oncologist in New York.

<http://www.eyecancer.com>

#### *Eyecancerforum*

A discussion form organized by patients.

<http://www.eyecancerforum.co.uk>

#### *General Medical Council*

This website defines the standards of care for doctors, therefore indicating patients' rights.

<http://www.gmc-uk.org>

#### *Government online – money, tax and benefits*

[www.direct.gov.uk](http://www.direct.gov.uk)

#### *Liverpool Tourist Information Centre*

The Mersey Partnership, 12 Princes

Parade, Liverpool, L3 1BG

Tel: +44 151 227 2727.

Website: [www.visitliverpool.com](http://www.visitliverpool.com)

#### *Liverpool Ocular Oncology Research Group*

Our own research website describing our research activities and our team.

<http://www.loorg.org>

### ***Macmillan Cancer Support***

Cancer support, information on benefits, finance, grants for expenses and prescriptions

[www.macmillan.org.uk/](http://www.macmillan.org.uk/)

### ***Medical Research Council***

This website includes an excellent explanation of correct procedures for handling data and tissue samples in research.

<http://www.mrc.ac.uk>

### ***NHS Choices***

Information from the National Health Service on conditions, treatments, local services and healthy living.

[www.nhs.uk/](http://www.nhs.uk/)

### ***Office of the Data Protection Commissioner***

<http://www.dataprotection.gov.uk>

### ***PubMed***

A database of summaries of medical literature.

<http://www.ncbi.nlm.nih.gov/PubMed/>

### ***RNIB***

A website with information and good advice on coping with sight problems.

<http://www.rnib.org.uk>

### ***The US National Cancer Institute***

An excellent site with information for doctors, nurses and patients.

<http://www.nci.nih.gov/>

### ***Work and Pensions Benefits Enquiry Line***

Tel: 0800 882 200

[www.dwp.gov.uk](http://www.dwp.gov.uk)

### ***World Medical Association***

This website publishes the Declaration of Helsinki, which defines the ethical principles for research involving human subjects. It also records its policy on a variety of other ethical and social issues.

<http://www.wma.net>

## **TELEPHONE NUMBERS**

### ***Benefits Enquiry Line***

Tel: 0800 882 200

Tel: 0800 220 674 (for Northern Ireland)

### ***Liverpool Airport***

Tel: 0870 129 8484

[www.liverpoolairport.com](http://www.liverpoolairport.com)

### ***Manchester Airport***

Tel: 0161 489 3000

<http://www.manchesterairport.co.uk>

### ***Merseytravel***

Tel: 0871 200 22 33

[www.merseytravel.gov.uk](http://www.merseytravel.gov.uk)

(Try Merseyside Journey Planner for personal itinerary).

### ***National artificial eye service***

Tel: 0845 6050561 for general enquiries.

Tel: 01253 651128 for appointments.

## Ocular tumours

The word 'tumour' merely means a lump, which may be a growth or another kind of mass, such as a blood clot or cyst.

A neoplastic tumour is a growth consisting of abnormal, new tissue. This can be benign or malignant. A benign tumour damages the eye without threatening life. A malignant tumour can spread to tissues around the eye and other parts of the body (i.e., metastasis).

### *Adenoma and adenocarcinoma*

These are very rare tumours arising from particular membranes inside the eye (i.e., retinal pigment epithelium and ciliary epithelium). They can be benign or malignant. If malignant, they can invade local tissues around the eye but do not usually spread to other parts of the body.

### *Congenital hypertrophy of the retinal pigment epithelium*

This lesion, which is also called 'chirpy', is a flat birthmark at the back of the eye. It is a large, dark, black spot, typically with discrete edges, often surrounded by a white 'halo'. It almost always entirely harmless and does not require any treatment. These lesions can give rise to adenoma or adenocarcinoma, but such an occurrence is extremely rare.



### **CHRPE**

#### *Cyst*

A hollow swelling, filled with fluid. This tends to arise behind the iris, pushing the iris forwards. Intraocular cysts are not usually neoplastic and do not threaten life.

#### *Disciform lesion*

This is a collection of fresh blood, clotted blood and scar tissue beneath the retina. It usually arises in more elderly individuals and is caused by abnormal veins growing beneath the retina.

#### *Haemangioma*

This is a benign tumour consisting of abnormal blood vessels. Fluid leaking from the tumour collects beneath the retina, causing distorted vision and blurred vision. If the amount of fluid beneath the retina is excessive and if the retina becomes totally detached, then abnormal blood vessels can develop on the iris. These can block the outflow of fluid from the eye to cause an increase in pressure, which can be painful.



### **Choroidal haemangioma**

The circumscribed variety usually becomes noticeable in middle age. A

diffuse variety occurs in younger patients as part of the Sturge Weber Syndrome, which is characterized by a red birthmark on the face.

Until recently, patients with choroidal haemangioma required radiotherapy but now we are able to achieve equally good results with photodynamic therapy, which is much more convenient.

### ***Leiomyoma***

A very rare benign tumour consisting of muscle.

### ***Melanoma***

This is a malignant tumour arising from melanocytes. Intraocular melanoma develops within the choroid, ciliary body or iris. Extraocular melanoma develops in conjunctiva or skin.



**Iris melanoma**

Intraocular (or ‘uveal’) melanomas affect about one person in every 2500 whereas conjunctival melanomas affect one person in every 125,000. Both tumours tend to arise in adulthood. The cause is unknown, although as with skin melanomas, ocular melanomas tend to be more common in individuals with fair skin, light-coloured eyes, and a tendency to sunburn.

Choroidal melanoma, if untreated, can:

- Cause retinal detachment, with blurred vision, distorted vision, flashes of light and a visual field defect;

- Perforate the retina, to cause vitreous haemorrhage (i.e., bleeding into the jelly of the eye), with floaters and blurred vision;
- Grow through the sclera (i.e., wall of the eye) to invade the tissues around the eye.



**Colour photograph of the back of the left eye showing a large choroidal melanoma.**

Ciliary body melanoma can:

- Press on the lens, to displace and distort the lens, which also becomes cataractous (i.e., cloudy) to cause distorted vision and blurred vision.
- Invade the iris to become visible to the naked eye;
- Invade the gutter draining fluid from the eye (i.e., trabecular meshwork in angle of anterior chamber) to cause raised intraocular pressure and loss of vision (i.e., secondary glaucoma).
- Spread to tissues around the eye.



**Ciliary body tumour**

Iris melanomas, if untreated, can cause:

- cataract; and
- glaucoma.

Conjunctival melanoma tends to:

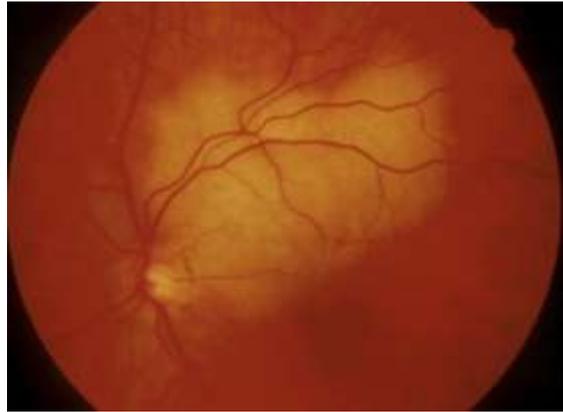
- Form a nodule in the transparent conjunctiva over the white of the eye or on the inner surface of the eyelid;
- Spread in a diffuse fashion in the conjunctiva;
- Scatter tumour cells to glands in the cheek and neck, where new tumours may develop.

Melanomas can spread through the blood circulation (i.e., ‘metastasise’) to the liver and other parts of the body. The chances of metastatic disease correlate with the clinical stage, the histological grade of malignancy and the genetic type.

### ***Ocular Metastasis***

This is a malignant tumour spreading via the blood circulation to the eye from a cancer in another part of the body, such as breast or lung.

This tumour is usually yellow or white. It grows rapidly and leaks large amounts of fluid to cause progressive loss of vision. It usually responds to a small dose of external beam radiotherapy, with improvement in vision. Another possible treatment is photodynamic therapy.

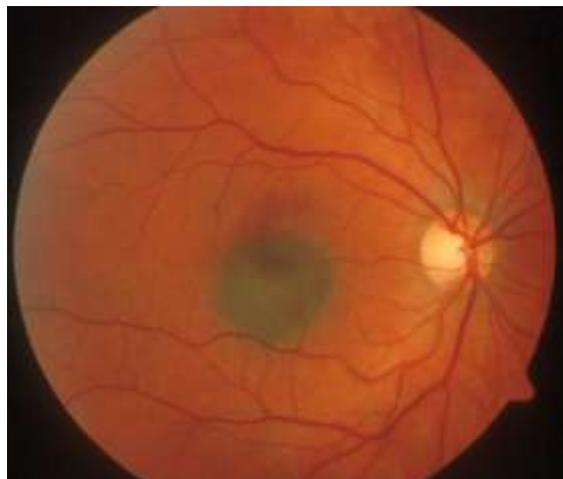


**Choroidal metastasis**

### ***Naevus (plural: naevi)***

This is a benign ‘mole’ arising from melanocytes. It forms a grey, brown or yellow lump, either in the choroid, beneath the retina, or on the iris. Choroidal naevi are very common, being present in about one in ten individuals. They differ from malignant melanomas in that they usually:

- have a thickness less than 2 mm;
- do not cause symptoms;
- do not leak significant amounts of fluid; and
- do not have large amounts of ‘orange pigment’ on their surface.



**Choroidal naevus**

Iris naevi tend to be smaller than malignant melanomas, and not more than 3 mm in diameter.

In some patients, the only way to be sure that a tumour is a benign naevus and not a malignant melanoma is to observe the lesion for many years to ensure that the tumour does not grow.

***Neurilemmoma***

A very rare benign tumour arising from nerve tissue.

***Osteoma***

A very rare tumour consisting of bone within the eye, usually next to the optic nerve.

***Retinoblastoma***

This is a highly malignant tumour developing in the retina of a baby or infant. It develops when both the chromosome 13 inherited from the father and the chromosome 13 inherited from the mother are mutated (i.e., two-hit hypothesis). In some babies, both mutations occur in the same cell, so that only one retinoblastoma develops. Other babies inherit one mutation from a parent, so that every cell in the body is abnormal and so that they tend to develop numerous retinoblastomas in both eyes as well as other cancers in various parts of the body.

---

## Evidence of excellence

### **Positive Feedback**

We receive many letters of appreciation from patients and their doctors. Some examples are:

*“I felt your clinic was an example of how the NHS could be run, and that when all we hear about is problems with the NHS, I would like to congratulate you on the efficiency of your department.” (Patient)*

*“I would like to take this opportunity to point out that the best recommendation for your service is the very positive feedback I hear from all my patients who have seen you. I congratulate you on this.” (Consultant Ophthalmologist).*

*“[My ophthalmologist’s] words to me at that time were that if I were a member of his family he would want me to go to Liverpool. In my case, due to your innovative ability and care, and that of your staff, the result is excellent and much better than I ever had hoped.” (Patient)*

*“I am absolutely thrilled with Mrs...’s wonderful result and would like to thank you very much for your excellent care and*

*for taking on such a challenging case.” (Consultant Ophthalmologist).*

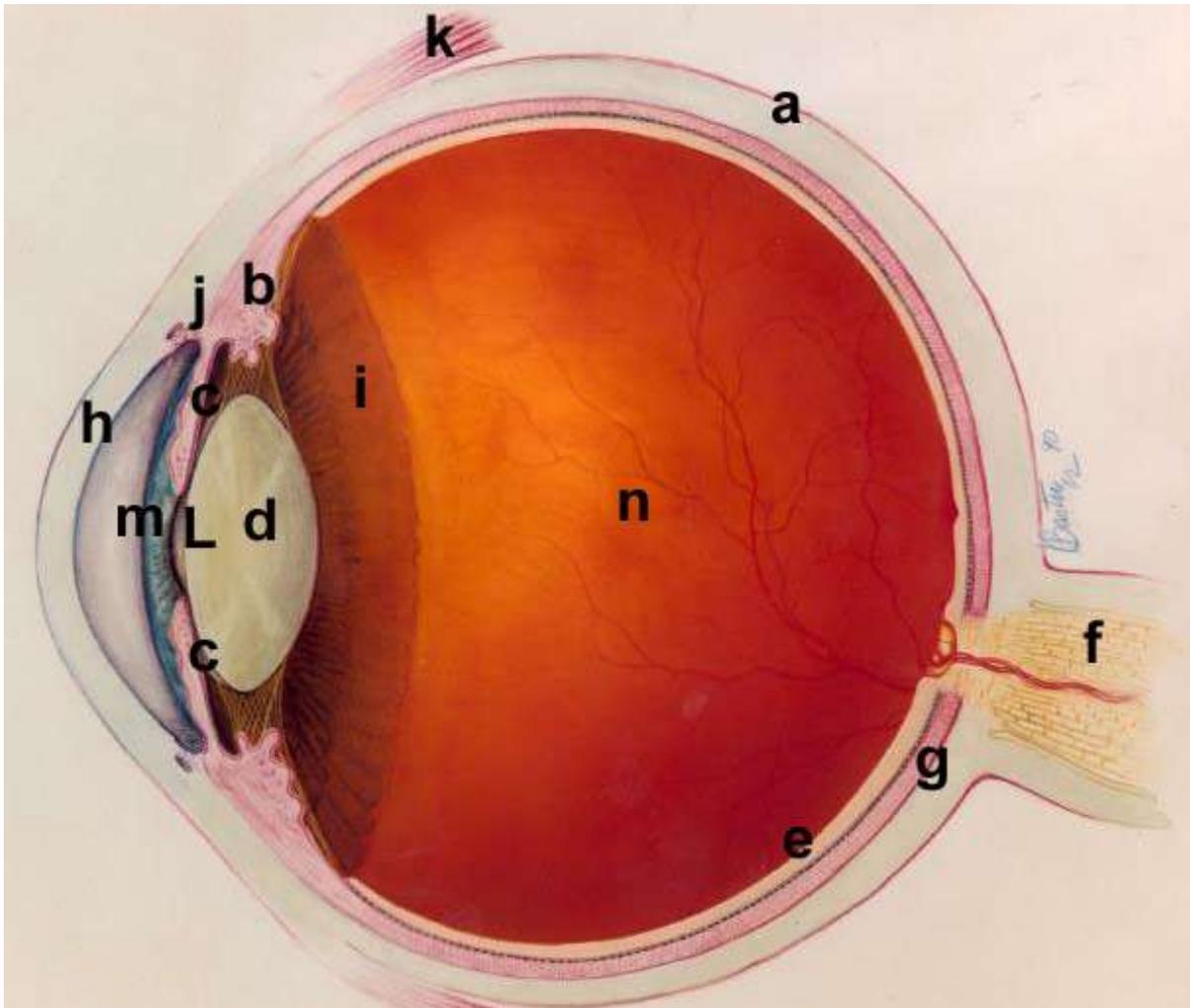
### **Peer Review**

In June 2006, LOOC was inspected by a team of peers from other centres and observers from NSCAG, which funds the service. We received a glowing report, which concluded:

*The Liverpool ocular oncology service is compliant with all the national standards and has many examples of excellent practice and innovation. Outcomes have been extensively audited, and the service is grounded on clear clinical leadership and a committed team. It is well supported by other services including the nationally designated ophthalmic pathology service.*

The full report can be found on our website ([www.eyetumour.com](http://www.eyetumour.com)) (see Latest Developments).

## Glossary



Cross-section of the eye, showing (a) sclera, (b) ciliary body, (c) iris, (d) lens, (e) retina, (f) optic nerve, (g) choroid, (h) cornea, (i) pars plana, (j) angle, (k) muscle, (L) pupil, (m) anterior chamber, (n) posterior chamber.

**Anterior chamber.** The cavity in the eye lying in front of the iris and lens.

### **Anterior chamber angle**

The margin of the anterior chamber, where the cornea meets the iris. This is where the 'trabecular meshwork' (i.e., gutter) drains water from the eye. Closure of the angle, for example, by tumour, causes glaucoma, which may be painful.

**Benign.** The tendency for a tumour to show slow and limited growth without breaking surrounding barriers and without seeding to other parts of the body.

**Cancer.** A group of diseases characterized by the formation of a neoplastic tumour having the capacity to invade surrounding tissues and colonize distant parts of the body.

**Cell.** The fundamental 'building block' of the human body. The cell is like a bag filled with fluid (i.e., cytoplasm) containing a number of structures, such as: (1) the nucleus, housing genetic material (as DNA coiled to form chromosomes; (2) mitochondria, dealing with energy; and (3) ribosomes, producing proteins.

**Choroid.** A vascular and deeply pigmented tissue lining, which is sandwiched between the retina and the sclera. The choroid is shaped like a cup or bowl.

### **Chromosome**

A rod like structure consisting of coiled DNA, comprising inherited genes encoding the structure and function of the cell. Each chromosome has two long arms and two short arms, all joined together at one point, known as the centromere. There are normally 23 pairs of chromosomes in each cell.

**Ciliary body.** A ring of tissue lying at the rim of the choroid and comprising the pars plicata, which is corrugated, and the pars plana, which is flat. The pars plicata pumps water into the eye and stretches the zonular fibres holding the lens to adjust the focussing of the eye.

**Conjunctiva.** A transparent membrane loosely covering the white of the eye and lining the inner surface of the eyelids.

**Cornea.** The transparent 'window' of the eye, through which the coloured iris and the black pupil are visible.

### **Cytogenetic studies**

These studies examine the chromosomes (i.e., the DNA) inside the tumour cells so as to identify abnormalities known to be related to tumour behaviour. For example, metastatic disease from uveal melanoma occurs almost exclusively in patients whose tumour shows partial or complete loss of the third chromosome (i.e.,

'monosomy 3'). Gain in the long arm of chromosome 8 (i.e., 8q) is also associated with a poor prognosis, especially when this occurs in association with chromosome 3 loss. In contrast, gains in the short arm of chromosome 6 tend to be associated with a good prognosis. Mutations occurring in tumour cells are not passed on to children, unlike mutations in eggs or sperm cells.

### **Fornix**

The fold where the eye meets the eyelid.

### **Fovea**

The central part of the retina, which provides detailed vision for recognizing faces, reading, watching TV, etc.

### **Glaucoma**

Excessive intraocular pressure on the optic nerve, causing visible damage to the nerve and visual loss, which may occur with or without pain.

### **Haemangioma**

A benign tumour consisting of blood vessels.

**Iris.** The coloured curtain regulating the amount of light entering the eye.

**Lens.** The transparent structure lying immediately behind the pupil, which focuses the image upon the retina.

### **Lymphatic system**

A system of fine tubes conducting milky fluid (i.e., lymph) from the tissues first to nearby lymph nodes (i.e., 'glands') and then to the major veins, near the heart.

**Malignant.** The tendency for a tumour to behave in an aggressive fashion, growing to a large size, breaking barriers to invade surrounding tissues, and scattering seeds to other parts of the body to form metastatic tumours.

**Metastasis**

Spread of tumour from the site of origin to distant parts of the body.

**Multiplex ligation-dependent probe amplification (MLPA)**

A laboratory test we use to identify abnormalities in chromosomes 1, 3, 6 and 8. This tests many genetic areas simultaneously and is therefore more sensitive than some other methods such as FISH (fluorescence in situ hybridization). The results are not always easy to interpret, however, especially when borderline values are obtained.

**Neoplasm.** A tumour composed of an abnormal family of cells, which may behave in a benign or malignant fashion.

**Ocular.** Pertaining to the eyeball and its covering membrane, the conjunctiva.

**Oncologist.** A medical doctor specializing in the treatment of cancer.

**Oncology.** The investigation and treatment of cancer.

**Ophthalmologist.** A medical doctor specializing in ophthalmology.

**Ophthalmology.** The investigation and treatment of diseases of the eye and surrounding structures.

**Optic nerve.** The nerve connecting the eye to the brain.

**Orbit.** The bony cavity, padded with fat, which contains the eye, the ocular muscles, and any related blood vessels and nerves.

**Posterior chamber.** The cavity within the eye lying behind the iris.

**Prognostication**

This is the process of estimating a patient's chances of survival, retaining the eye, maintaining vision, and other aspects of health. In patients with uveal melanoma, future health is predicted by analyzing:

- clinical tumour stage, determined by tumour size and extent;
- histological grade of malignancy, assessed by microscopic examination of the tumour;
- genetic indicators of lethality, such as chromosome 3 loss and chromosome 8q gain
- chances of dying of old age or other disease, estimated by considering the age and sex of the patient

We have developed an online tool for predicting survival probability after treatment of uveal melanoma, according to all these factors.

**Pupil.** The central opening in the iris, through which light passes to reach the retina and through which aqueous flows from the posterior chamber to the anterior chamber of the eye.

**Retina.** The light-sensitive film lying at the back of the eye.

**Sclera.** The leathery, white bag forming the eyeball and containing all the intraocular structures. The sclera is shaped like a cup, which is closed by the transparent cornea at the front of the eye.

**Tumour.** A mass or lump, which may consist of blood clot, neoplastic cells, a cyst.

**Vitreous gel**

This is the clear jelly filling the posterior chamber of the eye.

**Zonule.** A fine net basket containing the lens.



