

# OCULAR MELANOMA: COPING WITH DIAGNOSIS



**12** THINGS  
YOU NEED  
TO KNOW

A GUIDE  
WRITTEN  
BY PATIENTS  
FOR PATIENTS



*United Against Ocular Melanoma Cancers*

# ABOUT THIS BOOKLET



If you or a loved one has recently been diagnosed with eye cancer, you are probably reeling from the shock. People often describe this time as a 'whirlwind' or a 'roller coaster'. There is so much to take in with everything moving so quickly.

This document has been written from a 'patient perspective' by a group of ordinary people who have also been diagnosed with ocular melanoma.

We are not medical professionals, and this is not medical advice. But we do understand what you are going through. At a time when it can feel as if your entire world has been turned upside down, we hope this information might help you feel a bit more in control.

This booklet has been designed and distributed by OcuMel UK on our behalf.















United Against Ocular Melanoma Cancers



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**F**irst things first. Right now, everything will be focused on treating the cancer in your eye. That's how it should be but it is important to understand what you are dealing with.

Ocular Melanoma (OM) is a rare cancer. There are two types of ocular melanoma:

- Uveal Melanoma (UM)

- Conjunctival Melanoma (CM)

...so it is important you understand the two types are different. Uveal melanoma affects the structures in the middle layer of the eye – it may also be called choroidal, ciliary body or iris melanoma. Although Uveal Melanoma is seen as a melanoma, it behaves differently to skin melanoma and should not be viewed in the same way.

Conjunctival Melanoma is less common and is more like skin melanoma in the way it behaves. The treatments, follow-up scans and if needed, further treatments are all different to those offered to patients with uveal melanoma.

The causes of this disease are not really understood, and unfortunately there is nothing you could have done to prevent it. It's just one of those things.

Treatment of the cancer in the eye is usually successful. However, long term outcomes vary. Around half of all patients will never be bothered by this cancer again. The other half will eventually develop metastatic tumours. This means that the cancer cells start growing somewhere

else in the body. This can happen at any time in the 15 years after the first diagnosis, or even longer. There is currently no cure for metastatic OM but more promising treatments are becoming available.

It's difficult to deal with this information on top of a diagnosis, but it matters. As well as selecting a treatment for your eye, now is the best time to make a decision about prognostic testing too (see #11). Going forward, once you have recovered from your treatment, it's important that you have a suitable surveillance plan in place.



## In the UK, eye cancer is treated at a specialist centre

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There are four NHS centres in the United Kingdom that treat eye cancer. They are:

- Moorfields Eye Hospital, London
- Royal Hallamshire Hospital, Sheffield
- Royal Liverpool University Hospital, Liverpool
- Gartnavel General Hospital, Glasgow

Some consultants in these centres also offer private treatment.

A specialist centre means that you can be certain that your treatment is in expert hands. It also means that most people will have to travel for treatment and for follow-up appointments. If you live in England and Wales, you will usually be referred to your nearest centre. If you wish, you can ask to be referred to another centre, either for treatment or for a second opinion. Referral of patients from Scotland to centres other than Glasgow need approval from NHS Scotland<sup>1</sup>.

Travelling long distances can be difficult financially for some patients – for more information on potential help, please see Care Costs on Page 22.

It's fairly safe to say that YOU are the person who is most interested in your health and well-being.

Whilst we have all experienced wonderful care from medical professionals, some of us have felt let down by 'the system'. Don't just assume everything will happen as it should. Be prepared to ask questions, and to chase if necessary – politely but firmly. If you don't feel able to do this yourself, ask a trusted family member or friend to do this for you.

Being your own advocate starts from the moment of referral. As a suspected cancer patient, you should receive an appointment and be seen within 31 days of being referred. There is nothing to stop you calling the centre after a few days to find out when you are likely to be seen. A quick phone call can put your mind at rest, whilst if there's a problem, you can do something about it.

Being your own advocate continues long after your treatment is over. There might be ongoing problems or complications with your eye that need attention. You might need help with the emotional or financial impacts of cancer. You must make sure you are happy with your ongoing surveillance programme. If the cancer recurs, seeking expert help quickly, including second opinions, is vital. It's quite possible that your GP and your local hospital have never come across an eye cancer patient before, so having access to people who really understand the disease – medical specialists and fellow patients alike – can really transform your experience of living with OM and give you the support you need to be your own advocate.



## You might not remember ANYTHING the consultant says!

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For many of us, the diagnosis itself comes as a complete shock. What might have started as a routine eye appointment at your local optician, then ends up with a referral to one of the four specialist centres. We endure hours of tests, culminating in that frightening diagnosis... usually all in a single day. It can happen so fast and can be very hard to hear what your consultant says. You might get home and find your mind is blank, which is hard if it's the only appointment before your treatment starts.

We are sorry if this advice comes a little late, but it is worth thinking about your future appointments.

### DOs:

- Consider ways to help you remember...
- Take a loved one with you
- Take a notebook
- Ask if you can record the consultation on your phone
- Ask if the hospital have someone that can help you take notes
- Make a list beforehand of the questions you want to ask, so that you don't forget anything
- Ask if the consultation can be recorded. Some centres offer this routinely and send you a copy afterwards.



## DON'T:

- Don't be afraid to ask for another consultation or a second opinion, if you feel this would help.

When looking for information, be careful which sites you visit. Go for trusted sources. The internet has lots of information about OM, but it's not always accurate, up to date, or easy to understand, and can lead to unnecessary worry. Asking questions is important, but who you ask is even more so.

Each hospital has a dedicated section for ocular cancers although the amount of information varies so you can use all of these sites for information:

- London: [www.moorfields.nhs.uk/service/ocular-oncology-eye-tumours](http://www.moorfields.nhs.uk/service/ocular-oncology-eye-tumours)
- Sheffield: [www.sheffieldocularoncology.org.uk](http://www.sheffieldocularoncology.org.uk)
- Liverpool: [www.rlbuht.nhs.uk/departments/medical-specialisms/eyes-st-pauls-eye-unit/departments/ocular-oncology/](http://www.rlbuht.nhs.uk/departments/medical-specialisms/eyes-st-pauls-eye-unit/departments/ocular-oncology/)
- Glasgow: <https://www.nhsggc.scot/hospitals-services/services-a-to-z/scottish-ocular-oncology-service/>
- OcuMel UK: [www.ocumeluk.org](http://www.ocumeluk.org)

Another useful resource is OcuMel UK's YouTube channel. Here you will find talks from previous conferences on all areas of ocular melanoma from expert speakers in their field.



## There's no such thing as a stupid question

There's also no such thing as too many questions. Seriously. Don't worry about being a nuisance. On the day of diagnosis, you'll be given the number of a specialist nurse. These people really are wonderful – they are knowledgeable, kind and they are there to support YOU. If you do not have this number, you can contact your hospital and ask to speak to the ocular oncology clinical nurse specialist.

Hospital	Contact Details
London	020 7521 4639
Sheffield	0114 271 1962
Liverpool	0151 706 3976
Glasgow	0141 211 0124

Write down all your questions and give them a call. Today. Tomorrow. The day after. Ask as much as you want, as often as you need. With your permission, the nurses will also talk to someone on your behalf – so if it's all feeling a bit too much, ask a trusted friend or loved one to ask the questions for you.

OcuMel UK runs a helpline (0300 790 0512) and has support groups on Facebook for patients and their loved ones. You can also ask questions, or just talk, to others. Other organisations, shown on the back page of this booklet, offer help too.

## Understand what to expect from your treatment

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Usually (although not always) you will be offered a choice of treatment options. Your consultant should discuss the risks and benefits of each option with you, including the impact on your quality of life. In simple terms, there are four main things to consider:

- 1: How successful will this be at treating the cancer in my eye?
- 2: Will the treatment stop the cancer from spreading to other parts of my body?
- 3: Will the treatment save my eye?
- 4: What will happen to my vision?



Your consultant will help to answer these questions for you personally. Here are some general thoughts:

- 1: All treatments are effective at treating the cancer in your eye, although a small number of tumours are resistant to some treatments. Treatment is more difficult if the cancer has spread outside the eyeball.
- 2: There is no known survival advantage between any of the treatments<sup>2</sup>.
- 3: For about two-thirds of people, eye saving treatment is possible. Generally speaking, the smaller the tumour, the better the chance of preserving your eye.
- 4: Almost all treatments will cause some loss of vision eventually. Just how much, and when, depends on the size and position of the tumour, and the treatment type.



The most common emotion once treatment has finished is one of relief, but once the roller-coaster of treatment is over you have to learn to live with your cancer.

Everybody is different and there are such a range of treatments that you can't say that you definitely will, or definitely won't, experience any of the following issues but here are a few things that other patients have mentioned.

### Physical

The long-term physical impact on the treated eye can include loss of vision, cataracts, glaucoma, and visual disturbances such as flashing lights and phantom images. The chances of you developing issues will depend on many factors such as the type, location and size of your tumour, and the treatment that you had. There is support and treatment available for many of these problems so talk to your consultant or specialist nurse. Some, like glaucoma, will worsen if left alone so don't put it off or downplay it, it is too important.

A lot of patients report fatigue and although much of this is thought to be psychological and a reaction to stress that doesn't make it any less real or debilitating. Give yourself time to adjust, be kind to yourself and rest when you need to. You may also want to ask your GP for blood tests to help rule out any physical causes.

Part of the physical treatment is the medicines; most people will find that they need to have eye drops immediately after treatment but there's a good chance that you'll need them for a lot longer. If you

have been prescribed painkillers after surgery, then there can be side effects such as drowsiness and constipation. This can be brought on by the medication itself and because you are less mobile when you stay in hospital. You are not alone if you experience this.

If you suffer any side effects, you can talk to your nurse, GP or pharmacist and they should be able to help.

## Emotional

We are all told that living with cancer can be difficult, but it is good to know that support is available. Your specialist centre may offer psychological support, and as well as getting support from OcuMel UK you can also approach organisations such as Macmillan and Maggie's. Some people are reluctant to ask for help but getting the right help can make a huge difference to your state of mind and quality of life.

Knowing that the cancer can spread or recur is a frightening thought and at some time each of us will struggle with this. Talk to a counsellor, the OcuMel UK helpline, or other patients, whatever works best for you but please know that this is normal and please know that you don't have to do this alone.

Your self-image can also be affected especially if your condition is outwardly visible, such as enucleation or a visible tumour at the front of the eye. How you deal with this will depend on who you are, some people wear extravagant eye-patches but others will try to minimise the impact. There is no one way to deal with it and the way that best enables you to continue with your life is the right way.





## Practical

Losing your sight is frightening and brings with it a host of practical problems such as needing adaptations in your home or worries about independence. If your sight in one eye is affected, it doesn't necessarily mean that you have to stop driving although you will still need to be able to pass the sight test. Adaptations to your home need not be big things, it can be as simple as an additional handrail on your stairs, or moving things around so that important items like kettles are on your 'good' side so that you can see them more easily.

If you are still in work and struggling, your employer is required by law to make reasonable adaptations for you. If you work in an office this might be a screen viewer that enlarges text or changing the location of your desk so that people can't approach on your 'bad' side. Each work setting will have its own challenges but little changes can make a big difference, so it is worth pursuing.

Although we have mentioned the most common issues, if you have any concerns please talk to someone on the OcuMel Helpline or contact your Specialist Nurse or GP.

The good news is that a lot of the problems that OM sufferers come across, can be resolved or reduced and that overall quality of life is still good.

Sometimes, diagnosis isn't possible using conventional methods, especially with smaller tumours. If your consultant feels the tumour is 'suspicious' but isn't sure if it's cancer, he or she might suggest 'watchful waiting'. This means that your eye will be monitored over time.

This does have advantages. It means you avoid unnecessary treatment. But it has one potential disadvantage, too. For this, refer back to #1. Eye cancer isn't just about your eye. If it really is cancer, treating it as early as possible might just give you a better chance of survival. If you have any concerns, talk them over with your consultant. Quite often worries can be resolved. Alternatives to watchful waiting are to ask for a second opinion and / or to ask for a biopsy. Second opinions can be arranged at another specialist centre, or it might be possible to see another doctor at the same hospital. The other alternative is to have a biopsy. This involves removing a tiny sample of the tumour and testing it in a laboratory. It can be done on small tumours (of around 1 mm in size) and is accurate at confirming a diagnosis, but it does involve an element of risk. A biopsy can also indicate if the cancer is likely to spread to other parts of your body in the future. See #11 for more about biopsy risks and prognostic tests.

A biopsy is not offered routinely at every specialist centre, so you might need to travel to another centre for the procedure. This can be arranged by your consultant or your GP.



## Don't worry too much about scans before your treatment

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As well as arranging treatment for your eye, you should talk to your consultant about arranging surveillance scans. Surveillance scans are designed to detect if there is cancer elsewhere in your body. If the OM spreads, it is called metastatic OM. If Uveal melanoma spreads, the liver is usually affected and there are several different types of scan that you could be offered. Your clinician will talk about what is most appropriate for you.

It doesn't make much difference whether you have a scan before or after treatment. Your first scan will almost certainly be clear. Even if it isn't, this probably won't change the treatment plan for your eye<sup>2</sup>. As with everything else, if you are worried about scans, speak to your consultant or your specialist nurse.

There are guidelines on the treatment and management of Uveal Melanoma. These can be found on Melanoma Focus' website [www.melanomafocus.com](http://www.melanomafocus.com).

This can all feel quite scary, but in fact it is rare to find that the cancer has spread at this stage. Various studies estimate that between about 1% and 7% of UM patients have metastatic disease that can be detected at the time of diagnosis of the primary tumour<sup>2</sup>. It is very unlikely for people with a small tumour, and a little more likely for those with larger tumours, but either way, it is unusual.



## Don't worry too much about treatment time either

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The specialist centre will see you and assess your eye within a month of referral and subsequently aim to organise any treatment required within a month. In our collective experience as patients, this can range from about one and six weeks.

You might feel concerned about this. Some people worry that their treatment is too slow, and that the cancer might spread. Others feel the treatment is too fast and feel pressurised to make treatment decisions before they are ready.

The good news is that, for most people, a few weeks either way really isn't going to make any difference. It would become urgent if you were experiencing any pain or discomfort. If you are worried, talk to your consultant or specialist nurse. If you are being treated on the NHS, you probably won't be able to bring your treatment date forward, but they will be able to reassure you about the timing of your treatment. If you need a little more time, in most cases it should be quite possible to accommodate this safely.



## Tests can give a good indication of your personal prognosis

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**R**emember #1 – eye cancer isn't just about the eye? Although most of us are at risk of the cancer coming back, on average, statistics show that it will reoccur for half of us. By testing the tumour, doctors are able to give you an indication on whether you are at a higher or lower risk of this happening.

In a way, this is a matter of personal choice. Do you want to know, or not? Some people do. Others don't. There is no 100% certainty either way. A 'good' result may not guarantee a cancer-free future, and a 'bad' result doesn't mean the cancer will definitely return. What the results can do is give you an idea of the probability of this happening.

There are other considerations though. If you are at risk, knowing this should make it easier for you to get a higher level of care, in terms of surveillance scans. Possibly more importantly, cancer treatments are becoming more specialised.

For the testing to happen, a sample of the tumour in your eye is needed. If you are having your eye removed entirely, then a sample can be taken after your surgery. If you are having eye conserving treatment (that is, the cancer cells are treated inside your eye) you would need to have a biopsy. This means that a small sample of the tumour is removed from your eye using a needle. The biopsy usually happens soon after your cancer treatment, because once the cancer cells are destroyed, it is often not possible to get a test result.



There are some risks associated with having a biopsy, including damage to the eye, loss of vision and accidentally spreading cancer cells elsewhere in the eye. These are unlikely to happen, but you need to weigh these up in deciding whether a biopsy is right for you. There are videos on OcuMel UK YouTube channel from speakers discussing their thoughts on biopsies. One such video from Professor Heinrich Heimann explains this topic well. You can of course discuss this more with your medical team.

Your consultant will discuss the pros and cons of prognostic testing with you, including the risks associated with a biopsy for you personally, and you will have some time to decide what is right for you. A biopsy is not offered routinely at every centre, so you might need to travel to another centre. This can be arranged by your consultant.



**T**ravelling long distances can be difficult financially for some patients. If you are already receiving certain benefits, you can claim the cost of your travel, and the cost for a chaperone, so you can attend hospital appointments if you need eye drops or any treatment.

You will need to visit the cashier office at the relevant hospital and you will need to bring a benefits letter dated within the three months, your appointment letter and the receipts for your travel costs.

Macmillan can also offer a one-off grant and so please contact them should you need further assistance.

Anybody who needs any ongoing medication following a cancer diagnosis, including eye drops, are exempt from prescription charges in England. This includes all medication, not just for medicines relating to your cancer. If you currently pay for your prescriptions, you can ask your Pharmacist or GP for a Medical Exemption Certificate (FP92A), which you can renew every 5 years. Further information can be found on [www.nhs.uk/nhs-services/prescriptions-and-pharmacies/who-can-get-free-prescriptions](http://www.nhs.uk/nhs-services/prescriptions-and-pharmacies/who-can-get-free-prescriptions).

You can also call NHS Health Costs helpline on 0300 330 134.

If you are experiencing any visual loss, your local hospital is likely to have an Eye Clinic Liaison Officer (ECLO) who can help with financial, emotional and practical support. To find your nearest ECLO, enter your postcode and the search word 'ECLO' on [www.sightlinedirectory.org.uk](http://www.sightlinedirectory.org.uk).

# SUMMARY



So that's it. Twelve things you need to know.

Actually, if you can't take any of this in, try not to worry. A cancer diagnosis is traumatic. Don't underestimate the impact. It can affect you physically, emotionally, socially, financially. Expect to feel all sorts of emotions, including grief, loss, anger, isolation and fear.

But know also that there are other people like you who have been where you are now, and who understand what it feels like. We are here for you, and we can offer support, advice and empathy.



### References:

1. NHS Standard Contract for Ocular Oncology Service  
[www.england.nhs.uk/wp-content/uploads/2013/06/d12-ocular-oncology-ad.pdf](http://www.england.nhs.uk/wp-content/uploads/2013/06/d12-ocular-oncology-ad.pdf)
2. Uveal Melanoma National Guidelines, 2022  
<https://melanomafocus.org/wp-content/uploads/2022/05/uveal-melanoma-guidelines-2022.pdf>

### Useful Organisations:

- **OcuMel UK** 0300 790 0512  
[www.ocumeluk.org](http://www.ocumeluk.org)
- **MacMillan** 0808 808 00 00  
[www.macmillan.org.uk](http://www.macmillan.org.uk)
- **MIND:** 0300 123 3393  
[www.mind.org.uk](http://www.mind.org.uk)
- **Samaritans (Freephone)** 116 123  
[www.samaritans.org](http://www.samaritans.org)
- **Maggies** 0300 123 1801  
[www.maggies.org](http://www.maggies.org)
- **Penny Brohn** 0303 3000 118  
[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)
- **RNIB** 0303 123 9999  
[www.rnib.org.uk](http://www.rnib.org.uk)
- **Cancer Research UK** 0808 800 4040  
[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

# MEMBERSHIP FORM

PART 1

## SECTION 1: Contact Details

Full Name (including title): .....

Home Address (including postcode): .....

.....

Date of Birth: ..... Email: .....

Home Phone: ..... Mobile Phone: .....

## SECTION 2: About You

Do you have ocular melanoma? Yes ☐ No ☐

Or, do you know someone with ocular melanoma? Yes ☐ No ☐

(If 'yes', please continue)

What is the name of the patient? .....

What is your relationship to them? (e.g. friend, son) .....

Are you interested in joining our online community? Yes ☐ No ☐

(A separate invitation will be sent by e-mail during working hours)

PLEASE TURN OVER AND FILL IN PART 2, SECTION 3

Once complete, please return  
by email to [info@omuk.info](mailto:info@omuk.info) or  
by post to OcuMel UK, 139 Langley Road,  
Slough, Berkshire SL3 7DZ

 **OcuMelUK**  
United Against Ocular Melanoma Cancers

Membership Form: Part 1

OCULAR MELANOMA: COPING WITH DIAGNOSIS

### SECTION 3: Contacting You

**Please tick as appropriate:**

- ☐ I would like to become a member of OcuMel UK and am happy to receive communications
- ☐ I am happy for OcuMel UK to hold my personal data and I understand my personal information will not be passed on to third parties, unless I give permission separately

**I would like to receive information about:**

- ☐ Fundraising and campaigns
- ☐ Services we offer, changes to our website and other information about OcuMel UK and our activities

**Please tell us how you would prefer to be contacted:**

- ☐ By post
- ☐ By email

Our yearly newsletter and annual AGM invitations are exceptions. These are usually sent by post.

**Please tick as appropriate**

- ☐ I have filled in sections 1 & 2 overleaf
- ☐ I understand that by returning this completed form, I will have the opportunity to opt out of further communications each time I am contacted by OcuMel UK
- ☐ I am aware that OcuMel UK's privacy policy can be found on [www.ocumeluk.org/privacy-notice](http://www.ocumeluk.org/privacy-notice), and I can contact them for a copy to be sent to me

Signed: .....

Date: .....





OcuMel UK is a registered charity supporting those affected by ocular melanoma. We aim to help patients and their families by providing accurate, up-to-date information and emotional support via our website, helpline and online forums. Our vision is a world where ocular melanoma patients are given the information, support and treatment they need.

Being a small charity, we get to know the people we support and some of the challenges they face. We have built a community within the UK for patients and their families. This community helps to remove isolation and shares knowledge on coping with vision loss, treatment effects and other related concerns. We have built relations with our counterparts in Europe, America and Canada, so our community has a louder voice and best practice can be shared.

OcuMel UK operates a membership system which is overseen by a fantastic Board of Trustees, the majority of whom are ocular melanoma patients and family members. You can apply to become a member, at no cost, through our website or by completing the form in this booklet. As a member, you, or a family member, can attend our yearly conferences and access help from our psychological support service. We know this can be a difficult time for people, so please do reach out.

We are here for you, so please know you are not alone, and you can talk to people who have gone through similar experiences.







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**E [info@omuk.info](mailto:info@omuk.info)**

**f [facebook.com/OcuMelUK](https://facebook.com/OcuMelUK)**

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