

When people are diagnosed with uveal melanoma (UM), it is very common to have questions such as what UM is, what causes it, what symptoms can occur, and what treatment options are available.

This frequently-asked-questions (FAQs) guide provides some example questions on some of the most frequent topics that patients diagnosed with UM may want to know more about.

In addition, if you have other questions that aren't covered here, please let your doctor or healthcare professional (HCP) know and they can share more information with you – there is space provided at the end for you to write down the questions and answers.

Q What is uveal melanoma, or UM?

UM is a rare type of eye cancer found inside the middle layer of the eye wall — this is called the uveal tract.¹
UM develops if the cells in the uveal tract start to grow abnormally, forming a cancerous tumour.¹

What causes UM?

The cause of UM is not yet known, but there are some risk factors that can increase the chance of it occurring. These include light-coloured eyes, fair skin, an inability to tan, older age, inherited skin disorders, and genetic mutations.^{1,2}

Environmental factors like a high level of exposure to sunlight, ultraviolet, or blue light may increase the risk of developing UM, but this remains unclear.² People of Hispanic, Asian, or Black ethnicity have a lower risk of developing UM compared to those of White ethnicity.¹

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What are the most common symptoms of UM?



Symptoms can vary between different people. Some people with UM experience a range of symptoms, but many do not experience any symptoms at all.²

However, UM can cause distortion or loss of vision, visual light flashes or floating specks, a visible dark patch in the iris (coloured ring at the front of the eye) that may grow over time, pain or pressure sensations in the eye, or changes in eye shape or colour.^{2,3} Other symptoms may also occur.^{2,3}

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Are there different stages of UM? If there are, what are they?



UM can be defined by its size (you may hear doctors or nurses describe UM as small, medium or large), or by how far it has progressed.⁴ Early or localised stage refers to UM that is still confined to the eye, while advanced stage describes UM that has spread outside the eye, including to other body parts.⁵ Advanced UM includes UM that has grown into areas beyond the eye (locally advanced UM) and UM that has spread to distant body parts like the liver (metastatic UM, or mUM).⁵

If the UM spreads to other parts of the body that are distant from the eye, such as the liver or lungs it is called "metastatic UM", or "mUM" for short. UM that goes away with treatment but then comes back is called "recurrent".⁴

What are the UM treatment options and when is it possible to start treatment?

The main goals of treatment for UM are to destroy or remove the tumour, preserve vision, and prevent the cancer from growing or returning. The type of treatment depends on the tumour location, size, and stage, vision level in both eyes, previous UM treatments, the person's general health, and their personal preferences. 16

Radiotherapy is the most common UM treatment,⁷ and a specific type of radiotherapy called brachytherapy is the most common way of giving radiotherapy for UM.⁸ Brachytherapy uses a small radioactive disc (called a plaque) inserted onto the white of the eye.¹

Laser therapy, phototherapy and/or surgery may be options (alone or in combination).^{1,7} For UM that has come back in the eye, surgery is the most common treatment but radiotherapy is also an option.⁸

Immunotherapy, surgery, chemotherapy or ablative treatment may be options for UM that has spread to other parts of the body, which is also known as metastatic uveal melanoma (mUM).¹⁰

Following a diagnosis of UM, the aim will be to start treatment as soon as possible as earlier treatment achieves better outcomes.¹¹

What are the side effects of UM treatment?

Each type of treatment may cause side effects, and they may differ between treatments.¹ The doctor and health-care team will discuss and provide detailed information on any side effects or complications that may occur as part of these treatments.

What long-term outcomes are expected with UM?

Long-term outcomes may be better for UM that is detected early.² However, it is difficult to predict long-term outcomes for individual patients – because UM is very rare, statistics are based on small numbers of patients.³

UM outcomes depend on factors such as how early it is detected, the specific location in the eye, and age at diagnosis.²

Q Can UM spread to other parts of the body? What happens if that occurs?

UM can spread to the areas around the eye, structures called lymph nodes that are part of a system that helps you fight infection and balance your body fluid levels, or distant body parts (most UM cancers spread to the liver, but they may also spread to other places).^{4,14}

Patients whose UM spreads and can't be removed with surgery have to be treated with specific treatments. For UM that has spread to the liver, also known as "metastatic UM" or "mUM" for short, surgery on the liver to remove the cancer or treatment directly targeting the liver, including chemotherapy or ablative treatment, are options. Alternatively, if the UM spread involves a large amount of the liver or also other body parts, a type of treatment called immunotherapy which helps the body fight against cancer cells may be used although some patients may receive chemotherapy that goes throughout the body.

How does UM affect day-to-day life?

UM can cause both emotional and physical impacts for patients. Many patients worry about how their quality of life will be affected, particularly about the UM coming back after treatment, eye irritation, and vision problems.¹⁵

Physical impacts can include changes in eyesight or appearance (e.g., due to eye surgery), as well as fatigue from cancer or its treatment that can cause difficulties for many aspects of daily life.^{16,17}

It may be helpful for patients to discuss the possible impact of UM on daily life with their doctor or healthcare team.

- What should be discussed with family, friends and employers? What are the best ways to go about doing this?
- A It can be hard for people to know who to tell about a diagnosis of UM (both in their personal life and professional life, for people who are still working). The care team will be able to provide contact details of specialists that are trained to support people with cancer and can help with talking about the diagnosis.¹⁸

Patient groups can also provide information and support.



Are there any resources you would recommend for finding out more about UM?



Patient websites such as **Macmillan Cancer Research** and Cancer Research UK have helpful information about all aspects of UM that has been developed specifically for patients.

Patient support groups such as **Melanoma Focus** and **OcuMel UK** provide information resources and support networks for patients with UM.



www.melanomafocus.org



www.ocumeluk.org



Notes Use this space to write notes, questions, and record information.



References

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