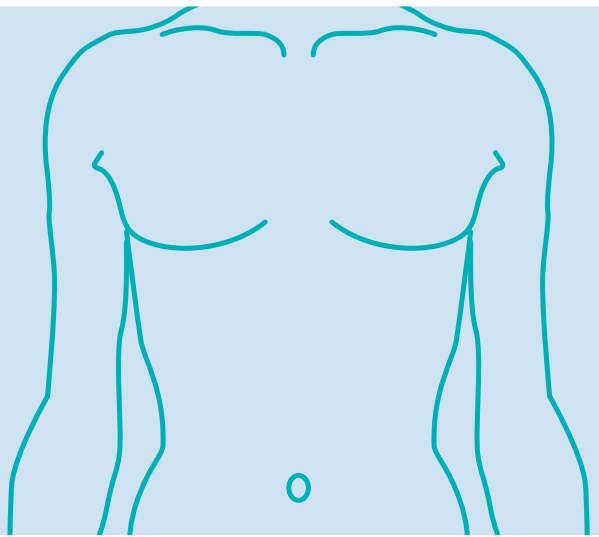


# Uveal melanoma that has spread (metastatic uveal melanoma)



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This booklet is for anyone with uveal melanoma that has spread to other areas. Your partner, family or friends may also find this useful.

Uveal melanoma is a type of eye cancer. If it spreads to other areas, it is called metastatic cancer. You may also hear it called stage 4 cancer, secondary cancer, or uveal melanoma that has metastasised.

Even though it is rare, there are still people who understand what you are going through and can support you. This includes experienced health professionals, volunteers and people with shared experiences. They can offer emotional support, discuss your diagnosis and treatment and advise you on practical matters.

Finding out you have uveal melanoma that has spread can be overwhelming and bring up difficult emotions. We have support services at Ocular Melanoma UK, and we are here for you every step of the way.



## Symbols

These symbols appear in this booklet so you can find out how to get more help:

CALL OUR HELPLINE



READ MORE ON OUR WEBSITE



*“I think life-changing events do make you stop and re-evaluate. And I think you need to allow yourself to do that. You need to be kind to yourself. It’s not your fault.”*

## What is metastatic uveal melanoma?

Uveal melanoma is a type of ocular melanoma, which is a type of eye cancer. Although it shares the name with skin melanoma, there are major differences between melanomas affecting the eye and those elsewhere.

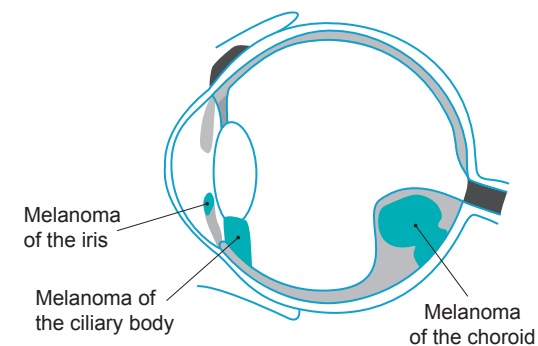


Figure 1 see page 52

There are three main types of melanoma affecting the eye and the surrounding structures:

- Uveal melanoma. These are cancers inside the eye. They are the most common type and may include the choroid, ciliary body and iris.
- Conjunctival melanoma. These are cancers of the conjunctiva. This is the clear, thin membrane covering part of the eye’s front surface and the eyelids’ inner surface.
- Orbital melanomas. These are cancers in the areas around the eye. They are extremely rare.

Find out more about the different types of ocular melanoma on our website: [www.ocumeluk.org](http://www.ocumeluk.org)



If cancer is metastatic, it spreads from the eye to other areas. The tumours are called metastases or secondaries.

Cancer can spread to nearby areas by growing directly through the tissue. Or, if cancer cells from the eye break away, they can travel in the blood or lymphatic system to a new area. The lymphatic system consists of hundreds of tiny channels and lymph nodes throughout the body. It allows fluid to drain from the tissues and returns it to the bloodstream.

The metastatic tumours are still the original type of cancer even when they are in a different area of the body. So, for example, if uveal melanoma spreads to the liver, it is still uveal melanoma, not liver cancer.

Uveal melanoma usually spreads through the bloodstream. It commonly spreads to the liver, although it can spread anywhere. Around nine in 10 people have liver tumours by the time they discover they have metastatic uveal melanoma.

We do not fully understand why most metastases develop in the liver. It may be because the liver filters the entire blood supply.

In contrast, conjunctival and orbital melanomas more commonly spread to the head and neck lymph nodes. They can also spread to lymph nodes elsewhere in the body or to the liver, lungs or skin via the bloodstream. Often these tumours spread more aggressively around the eye.

## Who gets metastatic uveal melanoma?

Around half of those with uveal melanoma develop metastases, and half do not. Metastases can happen years after your initial treatment. We do not know precisely why this happens. It may be that some cancer cells are not active or cause symptoms, and the first time they are noticed is on a scan.

Very rarely, a person may be diagnosed with metastatic disease when they first find out they have uveal melanoma. However, most of the time, metastases develop after treatment for the original cancer.

It is highly unlikely there was anything you could have done to prevent the cancer. We do not fully understand why some people develop uveal melanomas. Researchers do not think it is related to diet or lifestyle.

## Having treatment

Once uveal melanoma has spread to another part of the body, the aim of treatment is usually to control it and slow down its spread. Your doctor and healthcare team can take you through the different treatment options and what the benefits may be.

**Find out more about the different treatment options on page 19.**

## Looking after yourself

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You can still have a good quality of life with uveal melanoma that has spread. Besides having treatment for your cancer and symptoms, getting emotional support and finding other ways to look after yourself can also help. Let your doctor and healthcare team know about any symptoms you have. They can help you and refer you to a nurse specialist. These nurses have a specialist interest in your type of cancer and can help with advice about managing your symptoms.

There are also some simple ways you can help yourself:

### Coping with fatigue

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You may have extreme tiredness (fatigue) because of cancer and its treatments. Some things can help, including:

- ⦿ planning your day so you have time to rest
- ⦿ light physical activity to boost your energy
- ⦿ eating enough to give you energy
- ⦿ asking people for help with tasks you need to do
- ⦿ trying to get enough sleep by having a relaxing bedtime routine.

If you have fatigue, discuss this with your healthcare team, as there may be an easily treatable cause. Macmillan Cancer Support has more tips for dealing with fatigue.

### Physical activity

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Exercise, such as walking, has many benefits for your health and wellbeing. You can also do activities at home, including Pilates, yoga, or seated exercises.

If you usually do more vigorous exercise, you may be able to continue at first. But it may be helpful to think about changing your routine so it does not make you too tired.

Your doctor, nurse or physiotherapist can advise you on how much to exercise and how to exercise safely. You could ask to be referred to a physiotherapist for specialist advice.

### Relaxation

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Taking time for yourself and doing things you enjoy is important. This could be related to your hobbies or interests, learning, or doing new things. Or activities that help you relax and take your focus off your illness, such as reading, watching TV, or doing a jigsaw puzzle.

You could plan treats for yourself and your family. Something To Look Forward To is a charity that

supports people affected by cancer and their families. It offers meals, fun activities, short breaks away and other gifts to help you make the most of life.

Complementary therapies may help you relax. You could try massage, reflexology, aromatherapy, mindfulness or breathing techniques.



*“I have to live on a day-to-day basis.  
I’m doing most things I want to do.”*

## Sleep

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A good night’s sleep can help you feel well-rested and improve your mood. But having cancer can make it harder to sleep. You may be worried or in pain. Or you may be dealing with the side effects of treatment, such as nausea.

There are several things you can do to improve your sleep, including:

- ⦿ Setting up good sleep habits. For example: make sure your bed and room are comfortable, avoid daytime naps if possible and avoid too much TV, phone or computer time before bed.
- ⦿ Relaxing and winding down before bedtime. Some relaxation exercises may help, such as progressive muscle relaxation.

If these things do not help, speak to your doctor or nurse. They may be able to refer you for other treatments.

The charity Mind has more tips for a better night’s sleep.

## Work

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Some people with metastatic uveal melanoma that has spread continue to work. Working can help you feel more like yourself and give you something else to focus on.



You have legal rights at work. Your employer must make reasonable accommodations, such as allowing time off for appointments or working reduced hours. These adjustments can help you maintain your job and support yourself and your family.

Macmillan Cancer Support offers more information and advice.

## Support with finances

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When you have cancer, it is natural to be concerned about money. Ask your clinical nurse specialist about benefits. They will help you or direct you to someone who can. They can also help with letters of support if you are claiming income protection or critical illness insurance.

The charities Macmillan Cancer Support and Marie Curie offer practical support with applying for benefits.



*“I’ve cut my days down to 4 days a week. I do my hours, and I might do the odd little thing at home if it’s urgent.”*

## Getting support

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Finding out you have cancer that has spread can bring up lots of emotions. It can be scary and distressing and often comes as a shock. Everyone is different and reacts in their own way.

Remember that you do not have to cope alone. Support is important. It can be helpful to talk with your family, and this helps them to give you support as well

There are many ways that you and your family can find support at this difficult time. Here are some options:

### 🕒 **Clinical Nurse Specialist (CNS):**

Your CNS is there to support your mental health and physical wellbeing. Often your CNS is your key worker and first point of contact. They should talk to you about psychological support.

### 🕒 **Holistic Needs Assessment (HNA):**

Your team should give you this questionnaire to highlight your concerns and needs. You should have a chance to discuss these with your nurse and plan together. They’ll offer you support and information at the right time and direct you to any services and organisations that may help. You can bring a carer, friend or relative to this meeting.

### 🕒 **Psychological support:**

Ask your nurse or doctor to refer you for other mental health support. You can also refer yourself through the NHS. Speak to your GP or see what your local hospital, hospice or cancer support centre offers.

### 🕒 **Other organisations:**

Other organisations offer support and information, including Maggie's, Macmillan Cancer Support and Cancer Research UK. There are also melanoma specific organisations that may have information on some melanoma treatments, such as Melanoma Focus.

### 🕒 **Talking to those close to you:**

People often want to help but may not know how. Let them know what they can do. Perhaps you need help with practical things, such as going with you to appointments, knowing what symptoms and side effects to look out for, or helping with jobs at home. Or you may just need them there to listen.

🕒 Macmillan Cancer Support has information on telling people you have cancer that might help.

🕒 Ocular Melanoma UK has a 'Family & Friends' Facebook group, and our helpline is open to anyone affected by ocular melanoma.

*"I think probably the best thing is just being able to talk to people in the same situation as you."*

## **OUR HELPLINE AND SUPPORT SERVICES**

Our helpline is run by staff and volunteers who understand what you are going through. We are here to offer a listening ear and can also provide information and support to friends and family who need support. We are here for you.

🕒 Call our helpline on **0300 790 0512** or email **helpline@omuk.org**

🕒 Ocular Melanoma UK offers free psychological support to members of Ocular Melanoma UK: **www.omuk.org/support**

🕒 Anyone affected by ocular melanoma can become a member through our website: **www.omuk.org/members**

🕒 Connecting with others. We run online support groups on Facebook, including a group for people diagnosed with uveal melanoma that has spread. We also run a community support programme where you may be able to meet with people online or in person: **www.omuk.org/support/**



## Your healthcare team

If you have regular ophthalmology appointments, these are likely to continue. You will have separate appointments about the metastatic disease.

An oncologist and an oncology team manage your care. These are medical professionals who specialise in cancer. They will work with a wider group of experts in a specialist hospital (or centre) called a multi-disciplinary team (MDT). They should be experienced in treating uveal melanoma and have links with your ocular oncology centre.

Only a small number of teams in the UK specialise in treating metastatic uveal melanoma. Therefore, most hospitals link to one of the major centres with specialist expertise. Ask your oncologist if they are in contact with a metastatic uveal melanoma specialist who can help with essential advice and guidance.

Your MDT coordinates your tests, treatment & follow-ups. They have access to the treatments and trials available locally and can refer you to any available nationally. Your MDT includes:

- **A medical or clinical oncologist:** This doctor specialises in treating cancer and can give chemotherapy or radiotherapy. Ideally, this should be an oncologist with a specialist interest in uveal melanoma.

- **A diagnostic radiologist:** a doctor who uses scans to diagnose illnesses, find abnormalities or work out the position of tumours.
- **A histopathologist:** a doctor who looks at cells under a microscope to diagnose cancers and advise on treatments.
- **A Clinical Nurse Specialist (CNS):** a nurse with specialist training and expertise in melanomas.

Your MDT can also refer you to:

- **An interventional radiologist:** a doctor who uses imaging to guide specific procedures to diagnose and treat disease.
- **A surgeon:** your team may already include a liver (hepatobiliary) surgeon, or you may be referred to one. They are surgical doctors who specialise in treating liver and biliary system conditions.

You should have a named key worker who is your first point of contact for any questions or concerns. Often this is your Clinical Nurse Specialist (CNS). They can also refer you to other health professionals, such as dietitians, physiotherapists, or psychologists.

You should have their contact details, including telephone and email addresses. They will advise you who to contact if they are unavailable. Your key worker is responsible for communicating between the different cancer centres, your GP and your local hospital.

## Your appointments

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When you attend appointments, you can have a family member, friend, or carer with you. Your appointment could be in-person, by phone or by video call.

You can use your appointments to ask questions. For example:

- ⦿ What are the risks and benefits of tests and treatments?
- ⦿ What are the side effects of treatment?
- ⦿ What treatments are available nearby or at other centres?
- ⦿ What charity or mental health support services are available?

Write down your questions beforehand and take a pen and paper to make notes while you are there. You will be given written information at your appointment, including a follow-up letter summarising what the doctor said.



*“If there’s a few things I want to ask, I find it easier to write it down.”*

## Treatment for metastatic uveal melanoma

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Before a treatment plan is decided, you might have a biopsy. Your doctor takes a small sample of tissue to look at under a microscope to confirm the diagnosis of metastatic uveal melanoma.

You will also have scans and tests, such as blood tests. You might not need a biopsy if your scan shows that you very likely have metastatic uveal melanoma.

### Waiting for results

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Waiting for results can be challenging, and you may feel anxious. It usually takes about one to two weeks for the results to be thoroughly analysed. If you wait longer than this, contact your clinical nurse specialist to find out when your results are due.

There are ways to get support during this time. Connecting with others in our online community is a good place to start: **[www.omuk.org/support](http://www.omuk.org/support)**

Your multi-disciplinary team looks at your test results and assesses which treatments are right for you. Your options depend on the cancer type, where it has spread, any previous treatments and blood test results. They will also consider your age, overall health and what you want.

## Types of treatment

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There are two main types of treatment to control cancer.

### 🕒 **Targeted treatments:**

These treatments focus on the parts of the body where there is cancer. For example, many treatments focus on the liver as this is the most common place for cancer to spread.

### 🕒 **Systemic treatments:**

These treatments attempt to kill cancer cells anywhere in the body. They can help people whose cancer has spread to more than one area or when targeted treatments are unsuitable.

Researchers are exploring treatments for uveal melanoma. Your doctor should tell you about any current clinical trials you could join.

Depending on where your cancer has spread, you may be referred to another specialist, such as a liver (hepatobiliary) specialist.

Besides treatments to control cancer, there are others to ease symptoms. These are called palliative treatments. Some treatments do both. If you are offered palliative treatment, it does not necessarily mean there is not an effective treatment to control cancer.

You should be involved in treatment decisions. Your team will discuss the pros and cons of any treatment

options with you. You will have the chance to ask questions and understand what to expect before moving ahead.

It may not be possible for you to have a specific anti-cancer treatment. For example, you might not be physically well enough, or the treatment may be unlikely to help. Some people choose not to have anti-cancer treatment. Instead, they focus on their quality of life and managing symptoms rather than stopping cancer growth.



## Treatments aimed at the liver

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### Liver surgery

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Sometimes it is possible to remove part of the liver where the cancer is. This surgery is called a liver resection.

This surgery aims to completely remove the tumour from the liver. Therefore, it is usually only an option if the cancer is not too extensive. Otherwise, the surgeon would need to remove too much liver or leave some cancer, so there would be little benefit. Your liver must also be working well enough to cope with part of it being removed.

Different factors affect whether liver resection is an option. For example, it may depend on if there is cancer in other places and the treatment plan. You also need good overall health to have major surgery and anaesthesia. Everyone is different, so decisions should be made by a team with a specialist liver surgeon who can provide you with more information about what is best for you.

### What does surgery involve?

Before a liver resection, your doctor may first do a keyhole operation to check how much cancer there is in your liver. This is called a laparoscopy. The doctor may take a small biopsy sample of the area with the

tumour. Some people go home the same day of the laparoscopy, but others have to stay overnight for observation.

If you need a more significant operation, this may be either:

- **Keyhole (laparoscopic):**

The surgeon operates by inserting a camera and small instruments into your tummy through several small cuts (keyholes).

- **Open:**

The surgeon makes a larger cut (incision).

Your surgeon decides on the type of surgery depending on the size of the tumours and where they are. The main difference for you is the recovery time.

You can usually go home two to four days after surgery with keyhole surgery. With open surgery, you may need to stay in hospital for four to 10 days. Some people may need to stay for longer.

After surgery, you will continue to follow up with your oncologist or surgeon. Beginning two to three months after surgery, you will have regular MRI scans of your liver to monitor the cancer.



## Other treatments for the liver

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If you have cancer in your liver, but surgery is not an option, other treatments may help. Your team will discuss available options that may be right for you, including:

- chemotherapy directly to the liver (Chemosaturation)
- radiofrequency or microwave ablation
- hepatic artery embolisation
- radioembolisation (SIRT).

### Chemotherapy directly to the liver

Doctors can isolate the liver from the rest of the body's blood circulation and deliver strong chemotherapy medicines directly to the liver to treat visible tumours and microscopic cancer cells. This method of delivering chemotherapy does not affect the rest of the body and has fewer side effects.

It has different names, including:

- hepatic arterial infusion of chemotherapy
- hepatic chemosaturation
- chemosaturation therapy
- Percutaneous Hepatic Perfusion (PHP).

You may also hear the brand names CHEMOSAT<sup>®</sup> or Delcath.

## What does treatment involve?

You must be well enough to have treatment. So, you will have scans and tests in the weeks leading up to it. On the day of your treatment, you will be given a general anaesthetic. During the treatment, your surgeon temporarily isolates the liver from the rest of the circulation by blowing balloons up inside the veins around the liver and places a thin tube (catheter) into the hepatic artery, which leads to the liver. They can then deliver high doses of chemotherapy drugs through the tube. Another tube carries blood out of the liver. This is then filtered so the chemotherapy drugs do not affect the rest of your body. The blood is then returned to your body.

Afterwards, your team monitors you for any side effects and will follow up with scans and blood tests. The treatment is usually repeated several times, so it is as effective as possible. The average number of treatments is between three and six, with treatments every four to six weeks. The number of treatments you need depends on your scan results and if the cancer is still growing or has spread. The treatment is only available in a small number of highly specialised units. Most patients recover from the procedure within a few days, however, there can be side effects related to the chemotherapy or the procedure although serious side-effects are rare.

Currently, this treatment is not routinely available on the NHS for uveal melanoma. This decision will be reviewed, and your clinical team will discuss all treatment options with you.

## Radiofrequency ablation (RFA) and microwave ablation (MWA)

These similar treatments are an alternative to surgery. Although they do not involve a big operation, you will usually have a general anaesthetic so that you are asleep during the treatment.

Radiofrequency ablation (RFA) uses heat to kill cancer cells. Radio waves are a type of energy that can be used to heat up tissues inside the body. When they are focused on cancer cells, they can kill them.

Microwave ablation (MWA) uses microwave energy instead of radio frequency energy. Surgeons use it to heat the liver and damage cancer cells.

RFA may be better for larger tumours, and microwave ablation is slightly faster. Otherwise, the two techniques work similarly.

Researchers are still studying these treatments. There is little information on how well they work specifically for metastatic uveal melanoma. One small study showed they might help. However, they are often used to treat other types of cancer that have spread to the liver. Evidence from other types of cancer suggests that they work best on small tumours.

The surgeon delivers MWA or RFA with a probe that goes through the skin and into the tumour. You could have the treatment during keyhole surgery. This involves using a tube with a camera on the end called

a laparoscope. The surgeon inserts the laparoscope into your abdomen (tummy area) to see inside.

Before the treatment, you will have a general anaesthetic or a sedative to make you sleepy and a local anaesthetic to numb the area. You may have a general anaesthetic if you are having a laparoscopy or if it is likely to be too painful for a local anaesthetic. This may depend on the location of the tumour.

The procedure takes between 30 minutes and two hours, and you may need to stay in hospital overnight. You may need several rounds of treatment.

These treatments are generally considered safe, but most people have some side effects afterwards, including:

- pain or discomfort under the ribs or in your back
- feeling unwell with a raised temperature for a few days
- infection, but this is rare.

However, more serious complications are very rare.

Read more about microwave or radiofrequency ablation from Cancer Research UK.



## Radioembolisation (SIRT)

Doctors also call this selective internal radiotherapy or use the brand name SIR-spheres.

The treatment involves injecting tiny radioactive beads called microspheres into your liver through a catheter inserted into the main blood vessel (femoral artery) in the groin and then directed into the arteries inside the liver (hepatic artery). The beads are tiny and can only be seen under a microscope.

The beads travel to the liver and lodge themselves in the tiny blood vessels surrounding the tumours. They give off high doses of radiation which shrinks the tumours.

Radioactive beads can target the liver tumour without damaging the surrounding healthy tissue. However, you may have some side effects, including tiredness, pain in your tummy and feeling or being sick.

Currently, this treatment is not routinely available on the NHS for uveal melanoma. This will be regularly reviewed, and your clinical team will discuss all available treatment options with you.

## Other liver-directed treatments

Hepatic artery embolisation (HAE) uses microscopic gel beads to block off the arteries feeding tumours inside the liver. Hepatic artery chemo-embolisation combines chemotherapy and hepatic artery embolisation, by soaking the embolisation beads in strong chemotherapy solution, which is released into the tumour over 24-48 hours. It is also known as HAC and TACE (transarterial chemo-embolisation). You will usually have these treatments under local anaesthetic, or sedation, so you feel relaxed and sleepy.

The doctor inserts a fine tube into a blood vessel in your groin and threads it into the blood vessels inside your liver. They take an x-ray to check the position. They then release tiny beads soaked in chemotherapy drugs into the liver. The beads slowly release the drugs into the tumour and reduce its blood supply. The procedure can have side effects related to either the chemotherapy or the procedure. It is common to have discomfort on the right side of the tummy or under the ribs. Some people experience feeling slightly feverish, generally tired, or unwell in the first few days. More serious side-effects are uncommon.

This treatment is used for other types of cancer. However, it is not often used to treat uveal melanoma cancers in the liver. This is because it seems less effective than other treatments such as chemosaturation or radioembolisation (See page 24). However, it is available on the NHS in some specialist centres.



## Systemic treatments

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Immunotherapy and chemotherapy are systemic treatments. This means they kill cancer cells anywhere in the body. For most people, immunotherapy would be considered the first option.

### Immunotherapy

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Immunotherapy uses your own immune system to attack the cancer cells. There are different types of immunotherapies.

#### Checkpoint inhibitors

These are drugs such as ipilimumab, nivolumab and pembrolizumab. They were first developed for skin melanoma, but researchers found they can also treat uveal melanoma. They work by helping the immune system attack cancer cells.

You receive this treatment as an intravenous drip (infusion) into your bloodstream every few weeks. In some parts of the UK, it may be possible to have treatment at home. Usually, you will visit the hospital's outpatient department and go home after your infusion.

Depending on your situation and preferences, you may have the treatment alone or in combination with another. Your doctor can discuss the pros and cons of each option with you.

### Side effects

Being well enough to receive treatment is essential as immunotherapy often has side effects. They are usually caused by the immune system becoming over-activated and mistakenly attacking normal healthy tissue.

Milder side effects include skin reactions and flu-like symptoms such as fever. You could also experience more serious side effects, such as hormone changes or inflammation of the bowels (colitis), liver (hepatitis) or lungs (pneumonitis). Some side effects can be severe and can take a long time to recover from, and they may also require treatment in hospital.

Your oncologist will discuss these side effects with you when you consent to treatment. They will also explain what to do if you experience any side effects.

Read about ipilimumab, nivolumab and pembrolizumab from Macmillan Cancer Support, including the possible side effects.

#### Tebentafusp

Tebentafusp is an anti-cancer medication that is classed as immunotherapy. You might also hear it called KIMMTRAK or IMCgp100.

You will only be offered this treatment if you are HLA-A\*02:01-positive. HLA stands for Human Leukocyte Antigen, and HLA-A\*02:01 is a marker in your genes involved in the immune system. So you will need a blood test to check if you are HLA-A\*02:01-positive.

The treatment is given through a drip (infusion). You will need to stay overnight in the hospital for at least the first three doses. This allows the medical team to monitor you for any reactions or side effects. These include high temperature (fever), chills, low blood pressure and skin reactions such as a rash and itchiness. These side effects tend to settle down after the first few doses.

### Other types of immunotherapy

TILs and CAR-T are related therapy approaches. In both cases, immune cells are harvested and grown outside the body and then returned to the patient as a cancer treatment.

In TILs, these cells are the patients' own unmodified cells, in CAR-T, these cells are genetically modified and may come from a donor. There is insufficient evidence that either approach could help uveal melanoma patients; therefore, they are not currently funded by the NHS.

## Chemotherapy

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Chemotherapy uses anti-cancer drugs to kill cancer cells anywhere in the body. You may have chemotherapy through a drip (intravenously) or by taking tablets.

Chemotherapy can damage healthy cells as well as cancer cells. Often, these cells are in the bone marrow and digestive system. This is why you may experience side effects such as a low white blood cell count, which raises the risk of infection. You may also feel sick and very tired.

Your doctor will discuss the risks and benefits of chemotherapy with you so you can decide whether it is right for you.



## Clinical trials

Clinical trials are medical research studies involving patients. They allow researchers to find better treatments for people with metastatic uveal melanoma.

They may compare new treatments to current ones to see if they work and are safe. They will also examine side effects and whether the treatments help people feel better.

You can also ask your doctor if there are any trials you could join.

A clinical trial provides the opportunity to try new treatments. However, there is no guarantee that they are any better than the current ones.

Your team might also ask for your consent to store any of your tissue samples for research. The research may help improve future diagnoses and treatments.

Find out about current clinical trials on our website: [www.omuk.org/clinical-trials](http://www.omuk.org/clinical-trials)



## Best supportive care

Besides treatments to control the spread of cancer, you can also have palliative treatments to manage any symptoms. You may hear this called symptom control, best supportive care, or palliative care. It aims to make you feel as well as possible so that you can manage daily life.

Your oncologist may refer you to palliative care specialists, a district nursing team, or a local hospice team to help with your palliative care.

Not everyone with uveal melanoma that has spread feels unwell. So, you may not need palliative care if you are not having anti-cancer treatment. Instead, your team monitors you closely and may suggest best supportive care when it becomes necessary and if you agree.

Some people find the thought of palliative care upsetting. But, these services are not just for people at the end of their lives. They are available anytime during your care to help make you more comfortable.

Your palliative care team are experts in controlling symptoms, managing pain and offering emotional and practical support. They can also help you get care and support at home, live as comfortably as possible and improve your quality of life. The support is available both to you and your family.

## Side effects of treatments

Cancer treatments can cause side effects. Some are mild, but others are more difficult to cope with or may require urgent treatment.

Your team compares the benefit of any treatment with the risk of side effects. Before starting treatment, your team will discuss potential side effects with you so you know what to expect.

Sometimes you will need to stay in hospital overnight after a treatment. This allows your team to monitor you and see how you are responding. They will talk to you about which side effects to look out for when you are home. They will also tell you what to do if they happen and the contact numbers to call. Even if you are unsure about calling, it is always best to report side effects to your team.

There are often ways to manage side effects, but you may need to stop, change, or adjust your treatment if the side effects are severe.

## Getting an expert opinion

If you are unsure about your diagnosis or treatment plan, you can ask for another appointment with your doctor or key worker. If you still have doubts, you can ask your GP or oncologist to refer you to another doctor for a second opinion. This is not a legal right, but most doctors are happy to refer you to an expert in uveal melanoma. This may involve going to a different hospital or treatment centre.

It is normal for doctors to ask colleagues for their opinions, especially in complex or unusual cases.

Macmillan Cancer Support and Cancer Research UK have more information about getting a second opinion, including how to get one and prepare for your appointment.

You can also call our helpline. Our staff and volunteers can signpost you to the national guidelines for uveal melanoma and possible clinical trials so they can be discussed with your team.

CALL OUR HELPLINE





## Advocating for yourself

Uveal melanoma is rare, so not all health professionals are familiar with it or its treatment. Therefore, you might need to advocate for yourself or your loved one.

You may need to explain your condition, request referrals to another team or specialist centre, speak up about the treatments you want and chase test results and appointments.

Advocating for yourself may feel uncomfortable, but it is about knowing what you need and why it matters. Remember, you are the most important person in this experience, and it is normal to have questions and expect answers.

Things that can be helpful are:

- contacting your CNS
- showing this information to any health professionals who do not understand your diagnosis
- writing things down
- taking a family member or friend with you to appointments
- asking for contact numbers for health professionals.

Do not hesitate to contact us if you have any questions or want to discuss anything else.

*“You need to be your own advocate, but you also need to know the people closest to you actually understand what you’ve been through.”*



CALL OUR HELPLINE



## Talking about your prognosis and what this means

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Prognosis is your life expectancy or how much time you have left to live. It is different for everyone. It depends on multiple factors, including how far the cancer has spread, treatments you can have and any other medical problems.

Some people want to know their prognosis and its meaning, while others do not.

Speak to your Clinical Nurse Specialist (CNS) or another team member if you want to know more about your prognosis and next steps. Your loved ones or carer may also wish to discuss this with your team.

Understanding what happens next can help you be more involved in planning your treatment and organising any practical matters. Some people find it less stressful if they know what to expect. Everyone is different, and you may prefer to focus on the present and take each day as it comes.

Be careful of searching for information online. People tend to share their worst experiences rather than their best and sometimes, the information is not accurate or relevant to your situation. If you have any questions, it is best to ask your team.

## Practical matters

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If your cancer is incurable, you may have practical things you want to take care of. Some people find it helpful and feel more prepared and in control. It is good for everyone to feel that their affairs are in order, whether or not they have an illness.

You may want to consider the type of care you would or would not like. For example, would you like to be at home or in a hospice? This is called advance care planning.

You can speak to your team or call our helpline to learn more about how your health could change if the cancer spreads.

Other end-of-life wishes and plans you might want to think about:

- ⦿ Arrangement for a lasting power of attorney (enables other family members or friends to make medical or financial decisions on your behalf if you are unable to)
- ⦿ Funeral plans
- ⦿ Your Will (lets you decide what happens to your money, property and possessions after your death)
- ⦿ DNR (do not resuscitate) orders, see overleaf

DNRs can prevent problems for you or your loved ones later, especially if you have sudden changes in your health. For example, discussing whether someone would like a DNR order may mean a difficult conversation now but could make things much more peaceful later.

If you would like to discuss anything further, please contact your healthcare team or reach out through our helpline to talk.

CALL OUR HELPLINE



People coming to the end of their life and their loved ones can also find support through Marie Curie.



*“I have to have everything organised before I can relax. So, I was updating my Will and planning my funeral. It kept me busy. But it is done now.”*

## Ocular Melanoma UK Services

- Information on [www.omuk.org](http://www.omuk.org)
- Talk to us on **0300 790 0512** or [helpline@omuk.org](mailto:helpline@omuk.org)
- Talk to others in our online community
- Book psychological support
- Attend online events



## Useful organisations

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### Ocular Melanoma UK

(previously known as OcuMel UK)

- [www.ocumeluk.org](http://www.ocumeluk.org)
- Helpline: 0300 790 0512 (opening times)
- Providing emotional and practical support to people affected by ocular melanoma.

You may find the below organisations helpful.

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### Cancer Research UK

- [www.cancerresearchuk.org](http://www.cancerresearchuk.org)
- Helpline: 0808 800 4040 (Mon-Fri 9am-5pm)

Information for anyone affected by cancer.

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### Macmillan Cancer Support

- [www.macmillan.org.uk](http://www.macmillan.org.uk)
- Support Line: 0808 808 00 00  
(7 days a week, 8 am-8 pm)

Provides practical, medical and financial support for anyone affected by cancer.

### Maggie's Centres

- [www.maggiescentres.org](http://www.maggiescentres.org)
- Tel: 0300 123 1801

Centres around the UK and online offer free practical, emotional and social support for anyone affected by cancer.

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### Marie Curie

- [www.mariecurie.org.uk](http://www.mariecurie.org.uk)
- Support line: 0800 090 2309  
(Mon-Fri 8am-6pm, Sat 11am-5pm)

Provides care and support for people living with a terminal illness and their families, including nurses and hospices.

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### Melanoma Focus

- 0808 801 0777 Helpline:  
(Mon-Fri 1-2pm and 7-9pm, Sun 7-9pm)
- [www.melanomafocus.org](http://www.melanomafocus.org)

Melanoma resources for patients and carers.

## Mind

- ☉ Infoline: 0300 123 3393 (Mon-Fri 9am to 6pm)
- ☉ [www.mind.org.uk](http://www.mind.org.uk)

Advice and support about mental health.

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## Something to look forward to

- ☉ [www.somethingtolookforwardto.org.uk](http://www.somethingtolookforwardto.org.uk)

Support people with cancer and their families by providing a variety of gifts, such as tickets to attractions, restaurant meals, hotel stays and beauty treatments.

## Medical words explained

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**Bone scan:** If you have bone pain, your doctor may order a bone scan. It involves an injection of a radioactive substance followed by a whole-body scan. Bone scans show areas of cancer within the bones.

**Brain scan:** Depending on your symptoms, you may be offered a brain scan. It could be with an MRI, CT or PET scan.

**Choroid:** This is a thin layer of tissue that is part of the middle layer of the wall of the eye. It is between the white outer layer and the retina, the inner layer of nerve tissue at the back of the eye.

**Ciliary body:** A circular structure in the eye that is connected to the iris and located directly behind it

**CT or PET/CT:** CT stands for computerised tomography. This scan takes x-rays from different angles to create a 3D image. PET stands for positron emission tomography. It involves injecting a mildly radioactive substance into your bloodstream. It helps cancer show up more easily on the scan. You may have a contrast-enhanced CT or PET-CT of your chest, pelvis and abdomen.

**Dietitian:** Dietitians are qualified and regulated health professionals that assess, diagnose and treat dietary and nutritional problems. Most cancer hospitals have dietitians. They have the training and skills to look after

people with cancer. They can answer your questions and help you deal with any eating problems.

**Fatigue:** Extreme tiredness.

**Hepatobiliary:** Having to do with the liver, bile ducts, or gallbladder.

**Immune system:** Your immune system is a network of cells, tissues and organs. They help the body fight infections and other diseases.

**Iris:** Controls how much light enters your eye. It forms the coloured, visible part of your eye. Light enters through an opening in your iris called the pupil.

**Liver resection:** Surgery to the liver.

**Lymph:** A fluid that passes through the lymphatic system.

**Lymphatic system:** The lymphatic system works throughout the body. It is part of the immune system and also helps fight infection. It consists of a network of fine tubes called lymph vessels connecting glands called lymph nodes. Cancer cells may spread through this system.

**Metastatic:** Cancer that has spread from the part of the body where it started to other areas.

**Microscopic:** Things that are very small and can only be seen by using a microscope.

**MRI:** MRI stands for magnetic resonance imaging. These scans take very detailed pictures of the inside of your body using powerful magnets. You may have different types of MRI scans depending on the stage of your disease and treatment.

**Physiotherapist:** These health professionals help people with injuries, illnesses, or disabilities. They provide movement and exercise, education and advice. Some physiotherapists specialise in helping people with cancer.

**Psychologist:** A mental health specialist who helps people having emotional difficulties. They can help in stressful situations, such as coping with cancer. They can also help people with their relationships.

## About Ocular Melanoma UK

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Ocular Melanoma UK is a registered charity supporting people affected by ocular melanoma. Building on our legacy as OcuMel UK, we have changed our name to Ocular Melanoma UK and are more determined than ever to transform the landscape for people living with ocular melanoma.

We aim to help patients and their loved ones by providing accurate, up-to-date information and emotional support via our website, helpline and online forums. Our vision is a world where people with ocular melanoma can live, and live well.

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.

Our mission is to advocate for change by uniting the wider community against ocular melanoma cancers so that every person receives the treatment, information and support they need. We have established ourselves as a unique charity, able to advocate for patients struggling with aspects of their care.

If you'd like to talk through your experience, please get in touch by calling **0300 790 0512**.

This information booklet has been written by Anneliese Levy, Health Communication Specialist and Ocular Melanoma UK, with major contributions by:

### Clinicians

- Dr Paul Nathan, Consultant Medical Oncologist, Mount Vernon Cancer Centre
- Abolore Amuludun, Clinical Nurse Specialist-Melanoma (Skin/Ocular), Barts Health NHS Trust
- Dr Shanthini Cruz, Consultant Medical Oncologist Barts Health NHS Trust
- Prof Heinrich Heimann, Consultant Ophthalmologist, Royal Liverpool University Hospital
- Mr Neil Pearce, Consultant Hepatobiliary Surgeon, University Hospital Southampton
- Dr Ioannis Karydis, Consultant Medical Oncologist University Hospital Southampton

### Ocular Melanoma UK Members

- Mr Danny Boyle
- Mrs Diane Fishlock
- Mrs Lynne Cook
- Mrs Michelle Deans
- Ms Sarah Cummins



We would like to thank UM CURE 2020 and Diana Marques ([www.dianamarques.com](http://www.dianamarques.com)) for Figure 1, showing us how these tumours can appear in different locations on the eye.

We would also like to thank members of Ocular Melanoma UK's Eye Chat group for reviewing this information.

We make every effort to make sure that our services provide up-to-date, accurate information about ocular melanoma. This information should not replace medical advice, please speak to your medical team with any concerns or questions.

Email us at [info@omuk.org](mailto:info@omuk.org) for references to the sources used to write this booklet.

## 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? .....

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.org](mailto:info@omuk.org) or by post to Ocular Melanoma UK, PO Box 6136, Slough SL3 3LU

 **Ocular Melanoma UK**  
UNITED AGAINST EYE CANCER



## SECTION 3: Contacting You

### Please tick as appropriate:

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

### I would like to receive information about:

- Fundraising and campaigns
- Services we offer, changes to our website and other information about Ocular Melanoma UK

### 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 Ocular Melanoma UK
- I am aware that Ocular Melanoma UK's privacy policy can be found on [www.omuk.org/privacy-notice](http://www.omuk.org/privacy-notice), and I can contact them for a copy to be sent to me

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

## Notes



## United Against Ocular Melanomas

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If you or someone you know is living with ocular melanoma, we are here to help.

Our vision is a world where people with ocular melanomas can live, and live well.

If you would like to receive updates about living with ocular melanoma, treatments and medical research, then membership is for you, so please reach out if we can help in some way.

### Ocular Melanoma UK

Phone: 0300 790 0512

Email: [helpline@omuk.org](mailto:helpline@omuk.org)

Website: [www.omuk.org](http://www.omuk.org)

Facebook: [/OcularMelanomaUK](https://www.facebook.com/OcularMelanomaUK)



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Ocular Melanoma UK, PO Box 6136, Slough SL3 3LU

