Macular Society
Beating Macular Disease

Treatment for age-related macular degeneration

In some cases, age-related macular degeneration can be treated. Treatment must be given as soon as possible to limit the impact and progress.

This leaflet is available on audio CD.

You don't have to face macular disease alone. For the best information and support call us on 0300 3030 111.

Introduction

Age-related macular degeneration (AMD) is the most common cause of sight loss in the UK. There are around 700,000 people in the UK with AMD. The number is increasing as the population ages.

The macula is the most sensitive part of the retina. It gives us our central vision and the fine detail of what we see. When the macula is damaged, people may not be able to drive and find it hard to read, watch TV and recognise faces.

Dry AMD is a slow deterioration of the cells of the macula, often over many years. There is no medical treatment for dry AMD but research is going on around the world, including research funded by the Macular Society.

Wet AMD is another form of the condition. It is caused by tiny abnormal blood vessels growing into the retina which leak and cause scarring of the macula. A person with wet AMD can lose much of their central vision in a few weeks. There are now treatments for wet AMD which slow the progress of the condition in most people. Treatment has to

be given quickly, before there is permanent scarring to the macula.

The National Institute for Health and Care Excellence (NICE) Clinical Guideline recommends that people with suspected wet AMD should be referred to a retinal specialist immediately. If treatment is needed, it should be giving within 14 days of the initial referral. Optometrists who suspect someone has wet AMD should refer the person directly to a retinal specialist at a hospital and not refer via a GP.

Current treatments for wet AMD

Several drugs are used to treat wet AMD. They are known as 'anti-VEGF' drugs. VEGF is short for Vascular Endothelial Growth Factor. It is the substance in the body that is responsible for the development of healthy blood vessels. In wet AMD, too much VEGF is produced in the eye, causing the growth of unwanted, unhealthy blood vessels. Anti-VEGF drugs block the production of VEGF and stop the development of abnormal blood vessels. All anti-VEGF drugs need to be delivered directly into the eye.

The current method is injections, however new methods are being delivered. Don't worry, they are much less frightening than they sound.

In accordance with NICE AMD guidelines, all patients receive a standard 'loading dosage' at the start of their injection treatment: normally three or more consecutive monthly injections.

After this initial phase there are a number of treatment regimens that an ophthalmologist can choose. Each regimen has a subtle difference in the frequency of appointments. They also vary as to whether or not you have an injection at every appointment. The ophthalmologist will tailor treatment to individual patients and how their disease is responding to treatment.

Top tip – We recommend that patients ask their eye doctor, after their initial loading doses, what treatment regimen they are on, and what to expect at each appointment. From this, patients will be better able to understand the

timescale between injections and feel confident that they are not being overlooked in the clinic appointment system or missing any treatment.

Navigating the Heath Care System

It is important to know the different roles at the eye clinic and who can help, here is a brief guide of who is at the eye clinic.

Consultant Ophthalmologist
You may see a different person every time you attend the eye clinic; your care however will be overseen by a consultant ophthalmologist. You should have an ophthalmologist who specialises in AMD or retinal conditions to oversee your care.

Make sure you know what their contact details are in case you have any questions regarding your treatment. Their details should be on the paperwork you receive from the hospital.

Ophthalmic Nurse
More often than not, your injections will be administered by specially trained ophthalmic nurses. They are trained to assess and treat a

variety of sight loss conditions. They can also aid in the treatment of eye injuries such as a scratched cornea, and eye trauma. They can also give you tips and advice on how to treat any eye pain you have, or help with administrating eye drops.

Booking Clerk/ Receptionist

When you contact the eye clinic, it is very likely you will speak to a booking clerk or a receptionist. Sometimes this person may not comprehend the clinical need for your appointment and may not understand that you need one rapidly. If this is something you experience, you can explain that your treatment is time critical or try contacting your consultant or the hospital eye clinic liaison officer (ECLO) instead.

Eye Clinic Liaison Officer (ECLO)

Having an Eye Clinic Liaison Officer (ECLO) is a really effective way for eye clinics to help patients. An ECLO works closely with the eye clinic and the staff there and some external services such as the Sensory Team to help support patients with their sight loss.

Quite often, eye clinic staff may be unable to answer questions and provide emotional support to someone who has just been diagnosed. This is where the ECLO can step in and help.

They can also help you with your treatment schedule, when you have an appointment and liaise with the eye clinic to help get an appointment when you need one.

Unfortunately, not every eye clinic has an ECLO. However it is important for you to find out if there is one at your eye clinic, and if so, what are their contact details and working hours.

Top Tip – Find out the contact details of your consultant at the hospital and for the ECLO. If you experience a problem with your treatment appointments, these will be the best people to get in contact with first.

How is the injection given?

The majority of patients are treated at a hospital in a designated injection room. The eye may be examined first to check that an injection is

needed. If it is, the procedure may take place on the same day or you may have to return at a later, appropriate date.

When the injection is given, the patient reclines on a chair. An antiseptic solution will be used to clean the surface of the eye. The eye will be held open with a device called a speculum and anaesthetic drops are used to numb it. The patient looks to one side and the injection is given in the opposite corner of the eye. Most patients does not see the needle and the injection only takes a few seconds. Following the injection the eye will be cleaned with a normal saline solution.

While the majority of patients find this a painless procedure some people say the injections are uncomfortable and occasionally painful. Others experience discomfort for a while afterwards. Very occasionally there are more severe reactions, mostly due to allergic reaction.

Although a true allergic reaction to iodine (Betadine) is rare, some people find that it causes irritation to their

eye or skin. If you experience discomfort or pain after injections, tell your specialist or nurse (most injections administered by nurses). They may use a different local anaesthetic, saline or lubricant drops.

If none of these changes help, they may talk to you about using a different antiseptic called chlorhexidine, which doesn't contain iodine. Chlorhexidine kills a smaller range of microbes than Betadine. Research has shown an increased risk of eye infection, so your specialist should make sure you fully understand the possible risks. A drop of Betadine will still be used in the exact point the injection will be given. Saline will be used to wash the eye after the injection.

The eye can develop significant discomfort or severe pain about one hour or more after the injection. This may be due to one of a few possibilities, including a scratch on the cornea - the clear glassy part of the eye (called corneal abrasion) which may result in the skin in front of the cornea coming off due to the effect of the anaesthetic as well as dryness of the cornea.

The injection can cause the eye to become very 'dry' with a lack of lubrication. This can result in the eyelid sticking to the epithelium layer and when you open your eyes it may cause the layer to be damaged. Dry eye gel can be used to prevent this from happening after future injections, but please check with your eye care professional before using any product.

Excessive rubbing of the eye soon after an injection may predispose to an abrasion as the patient is unaware as to how much rubbing is taking place (as the eye is still numb).

Patients are advised to call the clinic or return to Eye Casualty immediately if they have any severe eye pain after an injection because treatment is required to reduce the pain and allow the scratch to heal properly, which may take up to 48 hours. The clinic also needs to know that this incident has occurred to avoid a recurrence,

Pain which develops in the eye 24 hours or more after the injection (up to about 1 week) requires immediate action. Pain, accompanied by redness and vision reduction, indicates an infection inside the eye (called

endophthalmitis) which requires urgent treatment – contact your eye casualty department and macular clinic immediately.

The following activities should be avoided for at least a week to reduce the risk of an infection:

- Showering
- Washing your hair
- Swimming – even with goggles
- The use of makeup

If you've been told you need injections and are worried, you can speak with people who've had injections for support and advice. Call our Advice and Information Service for more information.

Injections do not work if there is already longstanding damage to the macula. Around one in ten people with wet AMD do not respond to treatment.

When will injections stop?

There are two main reasons why patients who previously responded well to treatment may stop injections.

The first is if someone's macular has too much damage caused by the condition. This means a

person has lost the majority of their central vision in that eye and therefore injections are no longer effective and it is in the patient's best interest that treatment is stopped.

This can be upsetting news, we can support you with our free telephone counselling service, to find out more please contact our advice and information line on 0300 3030 111 for more information.

The second is if the blood vessels that are causing the damage have been successfully suppressed and they are no longer leaking onto the macula. Sometimes a hospital may refer to this as "going dry," "stable" or "inactive" This does not mean you have gone from wet AMD to dry AMD, but that the fluid has now "dried up." In this case, injections can be paused.

Hospitals may ask a patient to return every few months to monitor, or attend a local opticians to monitor their condition. The fluid can start leaking again which means injections may need to be started up again.

If your vision gets worse during this time, it is important to get in contact with an eye care professional so they can assess your condition and restart treatment if necessary. The amount of time injections are paused for is different for every person who is able to pause their treatment.

Top tip – We recommend that anytime your vision appears worse and you are currently receiving treatment, get in contact with your hospital, your treatment regime may need to be adjusted to help your condition as much as possible.

Laser treatments

On rare occasions some people may be offered laser treatment. A light-sensitive drug is injected into the arm. The drug travels to the eye where it is activated by a laser beam, shutting down the abnormal blood vessels. Most people need two to five treatments.

The treatment is only suitable for people with particular patterns of damage to the retina. However as this treatment carries a greater level of risk to the patient it is not routinely offered.

Future treatments

Researchers all over the world are working hard to find new and improved treatments for AMD. This includes researchers funded by the Macular Society. A lot of progress is being made but it may take some years before these treatments become available.

Treatments for wet AMD
One area that is being highly researched is the development of longer acting drugs for wet AMD. Longer acting treatments would allow patients to have fewer injections and trips to the eye clinic, and we are starting to see these new drugs become available.

Another way of reducing injections is an implant containing a drug reservoir. The implant is filled with an anti-VEGF drug and inserted into the eye. It then slowly releases the drug over the course of a few months, and will only need refilling every 6-9 months.

Research is also underway with the aim of moving away from the need for eye injections completely, but it is still in very early stages.
One way is to replace

injections with eye drops. However, this is complicated as our eye is designed to stop things getting into it, including drugs. Also, as the macula is right at the back of the eye, it is difficult to make sure that enough drug is able to make its way to the macula to be effective.

Replacing injections with oral tablets that patients can take once a day is another option. However, we need to make sure that these treatments are safe and won't have any effects on other parts of the body. Current eye injections mean the drug stays concentrated in the eye, so effects on the rest of the body are limited.

Gene therapy is another approach being researched to reduce the need for injections.

Treatments for Dry AMD

Among the options being explored are treatments to reduce the inflammation thought to lead to dry AMD. By reducing inflammation in the cells of the retina it's hoped we can reduce the progression of damage and sight loss. The methods being investigated include injections, tablets and gene therapy.

Stem cell treatment
Another promising approach is stem cell therapy. Many researchers around the world, including in the UK and USA, are looking at replacing cells that have become damaged or died due to macular disease. The hope is that the new eye cells will be able to maintain or even restore some vision.

Clinical trials of stem cell therapies are underway for both wet and dry AMD.

Biosimilar treatments
New forms of anti-VEGF drugs are now available to treat wet AMD, called biosimilars.

A biosimilar is a medicine developed to be highly similar to an existing biological medicine. Biosimilars might vary slightly from the original brand of medicine, but they work in the same way and they are equally safe and effective.

Biosimilars are already being used in the NHS for several conditions, used to treat a range of inflammatory conditions in the joints, skin, gut and eyes. A biosimilar goes through extensive tests in the

laboratory and in clinical trials to compare it with the original medicine. It must be proven to match the original medicine, and to work as well as the original in a disease that the original medicine is approved to treat.

Once testing is complete, the manufacturing company submits the results for approval. In the UK this is done by the Medicines and Healthcare products Regulatory Agency (MHRA).

Beating Macular Disease

Macular disease is the biggest cause of sight loss in the UK, with around 300 people diagnosed every day.

The Macular Society is the only charity determined to beat the fear and isolation of macular disease with world class research, and the best advice and support.

Our research programme is focused on finding new treatments and a cure

to Beat Macular Disease forever. To support people affected by macular disease now, the Macular Society provides a range of support, information and services:

The **Advice and Information Service (0300 3030 111)** is available Monday to Friday, 9am to 5pm. Alternatively, you can email help@macularsociety.org

Our **website** provides a wide range of information and resources for people affected by macular disease. You can also find out more about the services we offer. Visit it at **macularsociety.org**

Our network of over 400 **Macular Society Support Groups** stretches across the UK. Each one offers practical and emotional support for people with macular disease, from those living with it today.

Find your local group at **macularsociety.org/groups**

We provide a free, confidential **Counselling Service** over the phone. Call the Advice and Information Service for more information.

Working with you to Beat Macular Disease:

- We provide the best advice and information on living with macular disease.
- Macular Society Support Groups can help you to beat the isolation of macular disease, by connecting you with other local people who know what you're going through – offering support and companionship.
- Our research programme is focused on finding new treatments and a cure to Beat Macular Disease forever.

Macular Society

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