

Making a decision about **Wet Age-related Macular Degeneration (Wet AMD)**

What is this document?

This document is for you if you have been diagnosed with **Wet AMD**. This document is called a decision aid. It will help you decide between different treatments for **Wet AMD**. You should go through it and talk to your specialist to make a decision together.

Read pages 3 to 4 to help you make a decision about treatment.

Read pages 5 to 9 if you want more background information.

1 About Wet AMD and what I can do

Do nothing

- If you don't have any treatment your vision is more likely to get worse.
- Wet AMD won't make you go completely blind but you will likely lose sight in the centre of your vision. This can happen quickly, over a few weeks or months.
- Treatment may not work once your vision is bad.

Anti-vascular endothelial growth factor treatment (anti-VEGF injections)

- These are small injections in the white part of your eye.
- Your eye will be numb and you will not feel pain.
- If you choose treatment, the injections will start as soon as possible. The sooner you start, the better the results.
- You have one injection in each eye that needs treatment at each hospital visit.
- The injections take less than 30 seconds to administer and you will need to have them regularly to keep the benefit.

Your specialist may ask you if you want to begin treatment today.
Don't worry, this is completely normal.

2 About Wet AMD and what I can do

- Wet AMD is common. It affects the central part of your vision.
- The loss of vision is fastest during the early stages.
- It is caused by tiny blood vessels that grow in the back of the eye and leak fluid, causing scarring.
- Wet AMD does not cause total blindness – it only affects your central vision, you can still see ‘out of the corner of your eye’. But it can make things like reading or recognising faces difficult.
- Treatment aims to stop you losing the sight you currently have. It might improve sight for some people if caught early enough.

How does my specialist test whether my Wet AMD is getting worse?

They use an eye chart to see if treatments have been successful, they look at how many letters or lines you can read on the chart and compare that with what you could read at your last appointment.

They may also do a scan called an OCT which shows the back of the eye in detail.

They might also use a grid called an AMSLER to test for Wet AMD.

Potential benefits and risks of options

Do nothing

Do nothing means no treatment. Your sight is likely to get worse if you do nothing.

Anti-VEGF injections

There are a few different medicines your specialist might use for your injections. There is no difference in the effectiveness of these treatments but the number of injections required can vary with different medicines used in some people.

3 Potential benefits and risks of options

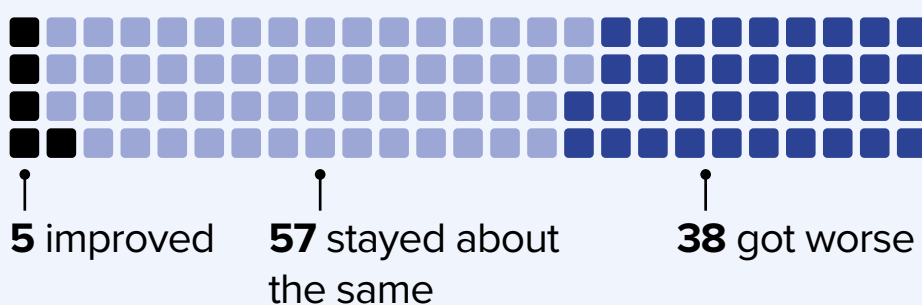
The numbers here come from a research study and a large UK audit. See page 8 for links to the evidence.

These numbers are **averages**. The potential benefits of anti-VEGF treatment depend a lot on how good your vision is now, before you start treatment. Ask your specialist how these numbers apply to you.

‘Improvement’ and **‘worsening’** here means how many people have a **significant change in their vision** (defined as being able to see 15 more or 15 fewer letters on the eye test chart) after 1 year, compared to when they were first diagnosed.

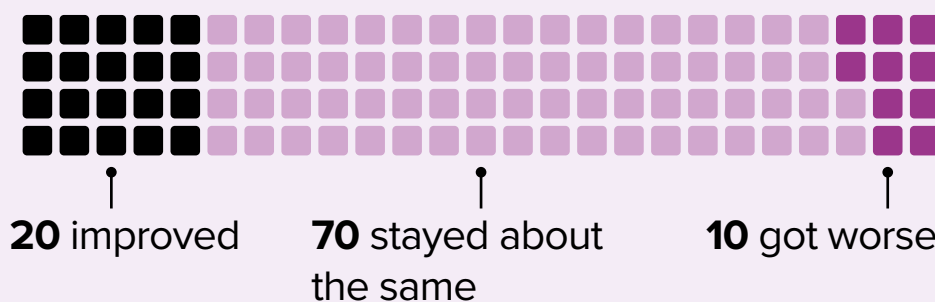
Do nothing

After **1 year** how was people’s vision affected?
(Out of every 100)



Anti-VEGF injections

After **1 year** how was people’s vision affected?
(Out of every 100)



4 Potential benefits and risks of options

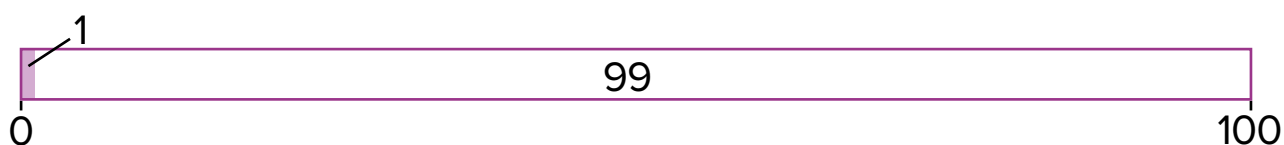
The numbers here come from research. See page 8 for links to the studies.

Risks of anti-VEGF treatment

For every **100** injections we'd expect



30 to experience **temporary symptoms** (first 48 hours) such as small specks in their vision, a red or sore eye, high pressure inside their eye needing temporary treatment.



1 to experience **inflammation** inside their eye – treated with drops and usually better within a month.

For every **10,000** injections we'd expect

4 to experience

- **A serious infection** in their eye (endophthalmitis) that often can cause loss of vision or other complications permanently
- **Bleeding inside their eye**
- **Glaucoma** (high pressure needing treatment or affecting sight)

0.01 to experience

- **Retina damage** such as retinal detachment
- **Cataract**
- Need for **further operation** or **procedure**
- **Permanent serious loss of vision**

5 More information

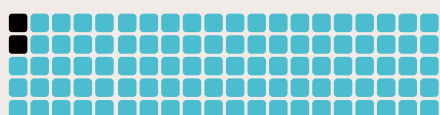
The numbers here come from research. See page 8 for links to the studies.

How many people have Wet AMD?

There are more than **500,000** people in the UK with Wet AMD.

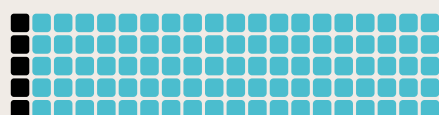
Aged 50 – 64

2 in every 100



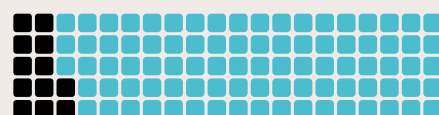
Aged 65 – 79

5 in every 100



Aged 80+

12 in every 100

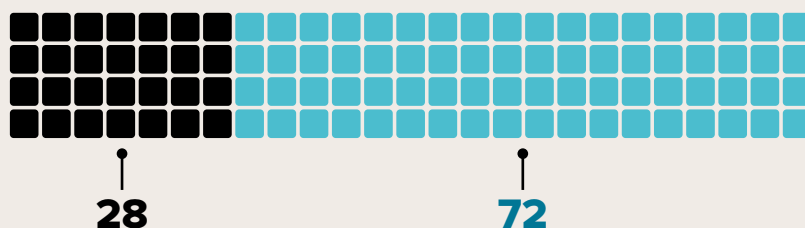


How did I get Wet AMD and how can I stop it affecting my other eye?

The exact cause is unknown but it usually happens as people get older and it's been linked to having a family history of AMD. If you stop smoking, control blood pressure and maintain a healthy weight, it may reduce the chance of it affecting your other eye.

If you took 100 people with Wet AMD in just one eye, after 5 years

We'd expect Wet AMD in
both eyes – 28 people
one eye – 72 people.



6 More information

What is anti-VEGF treatment?

- 1** Wet AMD happens when blood vessels start to grow in the back of the eye, where they are not supposed to be.
- 2** These tiny blood vessels leak blood and fluid and can damage the cells at the back of the eye.
- 3** A small injection of medicine into the white of the eye can help stop these blood vessels from growing.
- 4** The medicines are called anti-VEGF because VEGF (vascular endothelial growth factor) is what is causing the blood vessels to grow where they shouldn't be.
- 5** The anti-VEGF treatment prevents the VEGF produced by the body from working by blocking its effects on the blood vessels.

It is important to start your treatment early for best results

Finding the problem early and starting treatment early means the injections will work better. The damage and loss of vision is quickest during the early stages of Wet AMD.

On average, people lose five letters (one line) on an eye chart within the first three months after diagnosis.

How often will I need treatment?

On average people have **6–9** anti-VEGF treatments per year and they need treatment for **4 years** (regular injections).

At first you will have **3 or 4 injections 1 month apart.**

The time between injections will depend on how you respond to your previous treatment. Likely to be between **6 and 12 weeks apart.**

If your condition gets worse you might have to have more frequent treatments. If you want to know more about the injection you will have, talk to your specialist.

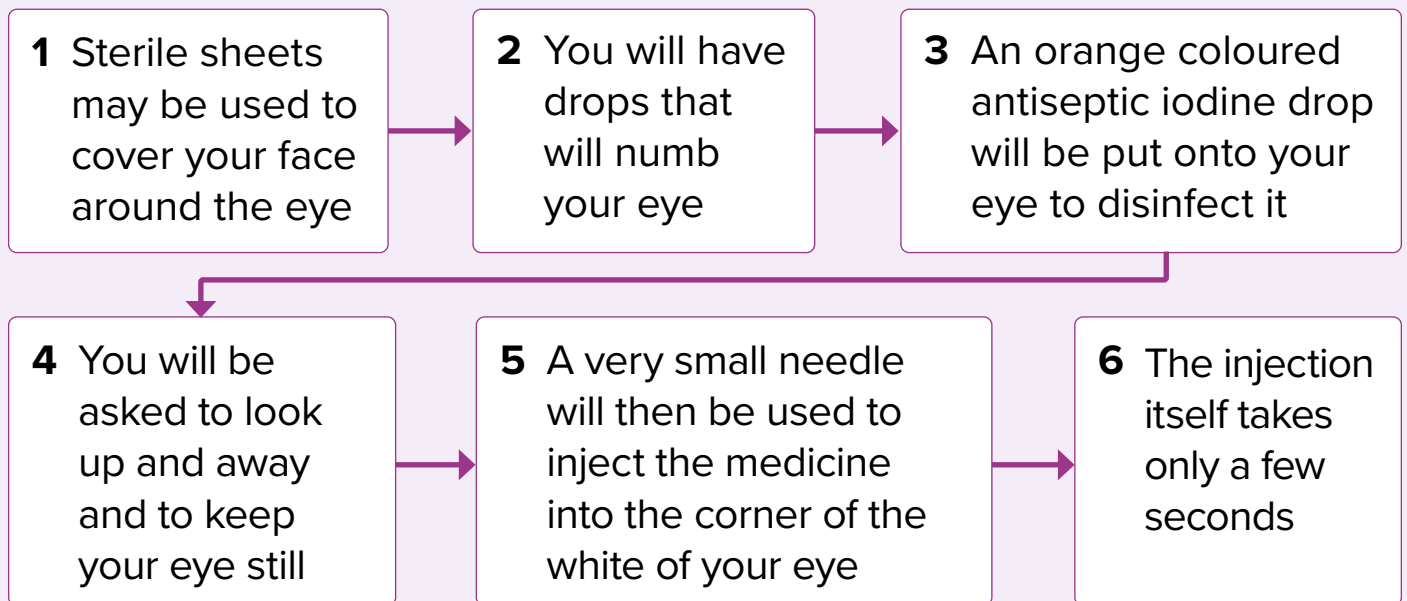
If you stop treatment whilst the wet AMD is active your vision will likely get worse. Talk to your specialist if you are finding it difficult to make the trips to hospital to have your injections. They will explain if it is possible to have longer time between injections or fewer trips.

7 More information

What happens on the day?

On the day of your appointment you can eat, drink and take your usual medicines as normal.

During the procedure:



Immediately after the procedure

- Your vision can be blurred for up to six hours.
- This means you must not drive for the rest of the day.
- You will make an appointment for follow-up for more injections.
- It is normal for the treated eye to feel slightly gritty, uncomfortable or watery and the white of the eye may be red for a few days after the injection.
- Drops that make the eye more comfortable – called lubricating eye drops – may be given to you to use.
- Some people notice floating dots or shadows in their treated eye, straight after the injection. These should gradually fade over the next few days.
- You shouldn't rub your eye in the first few hours after the procedure because your eye will still be numb and you won't feel how hard you're rubbing – you might scratch the eye.
- You should avoid showering (getting water and shampoo or soap in the eye) and swimming for 48 hours after the injection to reduce the risk of infection or irritation.

8 More information

Where did we get our data from?

UK prevalence data: NICE Guideline [NG82] 2018:

www.nice.org.uk/guidance/ng82/

Data on risk of developing Wet AMD in both eyes:

Pooled data from 1490 patients

www.doi.org/10.1136/bjophthalmol-2016-309729

Data for vision loss and gain:

Do nothing – clinical trial in which 238 patients received placebo (dummy treatment)

www.doi.org/10.1056/NEJMoa054481

Anti-VEGF injections – UK national audit (2024) with data for 18,360 treated eyes

[nodaudit.org.uk/sites/default/files/2024-03/NOD AMD Audit Full Annual Report 2024_0.pdf](http://nodaudit.org.uk/sites/default/files/2024-03/NOD_AMD_Audit_Full_Annual_Report_2024_0.pdf)

Data for vision loss in first three weeks after diagnosis:

Retrospective analysis of 1041 patients

www.doi.org/10.1016/j.oret.2020.12.020

Where can I go for more information?

Macular Society – Advice & Information

Tel: 0300 3030 111

RNIB – Sight loss advisors

Tel: 0303 123 9999 or say ‘**Alexa, call the RNIB**’
on an alexa-enabled device

Macular Society

www.macularsociety.org/

Royal National Institute for the Blind (RNIB)

www.rnib.org.uk/eye-health/eye-conditions/age-related-macular-degeneration-amd

9 More information

Contacts

Who is my specialist, ophthalmologist or Eye Clinic Liaison Officer?

.....

What are their contact details?

.....

Contact details of hospital transport
(if applicable)

.....

Next steps

What will happen to me next? (treatments/tests)

.....

When will these happen?

.....

When will I be reviewed next?

.....

What decision do I need to make today?
Or when do I need to make a decision?

.....

Questions for your specialist

These can be about any concerns you may have, for example
what you hope for from your treatment decision

Which websites/groups are good for information about this condition?

.....

.....

.....

Produced by:

Winton Centre for Risk and Evidence
Communication and NHS England
Date last updated: June 2024
Conflicts of Interest - None declared

Funding: NHS England

This decision aid was created with
input from patients and healthcare
professionals, representatives from
RNIB and The Macular Society