

**Name/Label:**



# **The Wet Macular Degeneration Passport**

**Helping you understand your  
condition and treatment**



# NHS Lothian

## Our Organisation

NHS Lothian provides a comprehensive range of primary, community-based and acute hospital services for the populations of Edinburgh, Midlothian, East Lothian and West Lothian.

NHS Lothian provides services for the second largest residential population in Scotland - circa 850,000 people. It employs approximately 24,000 staff.

At NHS Lothian we believe that working together across all areas of the health service is the best way to provide care for patients. Through an innovative programme of modernisation, we are developing into a single integrated health system.

[www.nhslothian.scot.nhs.uk](http://www.nhslothian.scot.nhs.uk)



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## **Purpose of the Wet Macular Degeneration Passport?**

This passport has been given to you by your eye doctor. It is your own record of your eye problems and treatment(s). It aims to help you track your care and support if you have any difficulties. It will also help you understand what Macular Degeneration is and how it affects you.

## **Passport Contents?**

This passport provides information about wet Macular Degeneration and its treatment, some useful contacts, and helpful lifestyle information. There is also space for you to note down any questions you may want to ask your doctor during appointments.

## **How should I use the Passport?**

You should take the passport to all of your clinical appointments. You may also wish to share the information it contains with family and friends. It may be useful to take it to any appointments you may have with your G.P. or Optician.

**It is important that you bring the passport with you every time you attend the Macular Clinic.**

# Your Eye Care Team

## Medical Staff



**Consultant  
Dr P. Cackett**



**Consultant  
Dr. A. Al-Ani**



**Consultant  
Dr M. Das**



**Associate Specialist  
Dr A. Ambrecht**

There will also be nursing, reception and imaging staff.

## **Your Medical Information**

If you are unable to complete the information requirements below then please ask your GP or Macular Clinic Staff to help

### **Summary of My Eye Health History**

### **Summary of My Medical History**

If you are unable to complete the information requirements below then please ask your GP or Macular Clinic Staff to help

**Eye Drops I am Taking**

**Medication I am Taking**

**Allergies**

## **What is Wet AMD?**

Wet age-related Macular Degeneration (wet AMD) develops when abnormal blood vessels grow into the macula. These leak blood or fluid which leads to scarring of the macula and rapid loss of central vision. Wet AMD can develop very suddenly.



**Normal Vision**



**Wet Macula Degeneration**

## **How is Wet AMD Treated?**

Wet AMD can be treated if caught early. Drugs are injected into the eye to stop the growth of the abnormal blood vessels. The injections are not as bad as they might sound. Giving these injections can help prevent damage to the retinal and loss of central vision.

Most people with Wet AMD require seven injections in the first year. Initially you will have a course of three injections a month for three months and then we will do an OCT scan.



Injections can be given in a variety of intervals normally monthly or two monthly. Your consultant will decide what is most suitable for you.

We will check how well your eye is responding to treatment either in a virtual clinic or a face to face clinic with a consultant. We have patient information leaflets which provide information on what a virtual clinic is and how it works. You are normally seen in either of these clinics a month after you have completed your cycle of treatment.

**The injection I am receiving into my  
Right / Left / Both eyes**

**is called:.....**

## Treatment Schedule

Treatment commences with x3 monthly injections. The majority of patients require ongoing treatment usually at a reduced frequency, i.e. One injection every two months.

It is very important that you attend all of your appointments.

If you do not have an appointment arranged for your next treatment, please phone the relevant hospital as soon as possible in order to arrange an appointment date for you.

PAEP Macular Clinic :      **0131 536 1373**  
SJH OPD1:                      **01506 524286**

## What happens at my injections?

The procedure itself normally takes 15 minutes, with the injection taking about 20 seconds. However, you should expect to be in the department for up to two hours - this allows for preparation before your procedure.

To get the injection, you will lie down on a couch. Local anaesthetic drops are placed in your eye to numb the surface.

Staff will clean your eyelids and the surface of your eye with an antiseptic solution to prevent infection, and then cover your face with a small sterile drape. A small clip called a speculum is used to keep your eyelids open during the procedure.

More local anaesthetic eye drops are placed into your eye.

The injection site is marked with a small calliper (measuring device). After this, you will receive the intravitreal injection.

Your vision will be assessed after the injection, by checking you can see hand movements or count fingers.

## **What should I expect after the injections?**

As the local anaesthetic wears off it is normal for your eye to feel gritty, uncomfortable or watery and the white of the eye may be red after the injection. This should settle within one or two days. There may be a red dot on the white of the eye where the injection was given and again this will settle within a day or two.

Sometimes a tiny air bubble can be introduced into the eye during the injection. This appears as a round dark floater in the centre of your vision. Do not be alarmed as this will get smaller and should disappear within 48hrs.

Please do not rub your eye after the injection as there is a risk you causing a scratch to the surface of the eye whilst the numbing drops are still working.

Some patients notice floating dots, flashing lights or shapes after the injection, these should gradually fade in the next two days.

All of these symptoms should improve on a daily basis.

## What you can do to make your eye more comfortable

- If necessary, you can take some painkillers - something you normally take for a headache should be fine
- Lie down and rest
- Lubricating eye drops.

## What if I have any problems?

If you are concerned or worried about anything after your injection, contact us on any of the numbers listed below.

### If you experience

- Increasing pain/ache in the eye
- Pus or discharge
- Red eye
- Deteriorating vision

Please contact the department immediately via the phone numbers listed below. These symptoms may be a sign of infection which is a serious complication.

Serious complications must be treated quickly to minimise damage to the eye.

Mon - Fri 8.30am - 4.30pm  
PAEP Triage - **0131 536 3751**

Mon - Thurs 8.30am - 5.00pm, Fri 8.30am - 13.30pm  
SJH OPD - **01506 524286**

Evenings, weekends and Bank Holidays  
PAEP E2 - **0131 536 1172**

## Frequently Asked Questions

### **What is the difference between wet and dry age-related Macular Degeneration?**

Most people over the age of 70 (about 75%) have dry macula degeneration. This is part of our natural ageing process. It is caused by a build up of waste material in the back of the eye.

Wet macula degeneration occurs when abnormal blood vessels grow underneath the retina at the back of the eye. We don't know why some people develop this and others don't. Lifestyle and genetics can be responsible, a small number of people could have **DRY AMD** and this may progress into **WET AMD**

### **Will wet-AMD affect my ability to drive?**

Ask your Consultant if your condition affects your ability to drive. You are legally required to inform the DLVA of your condition. If there are any doubts regarding your ability to drive the DLVA can arrange further tests.

### **What about my other eye?**

Research suggests that 20% of dry-AMD sufferers can convert to wet-AMD. We will therefore monitor both of your eyes to ensure that any changes suggesting wet-AMD indication will be identified and treated promptly.

## **What can I do to help my condition?**

- It is important for your general health to take regular exercise, stop smoking, maintain a healthy weight and to have a diet rich in fresh fruit, nuts and dark leafy green vegetables (such as spinach).
- Keep your blood pressure and cholesterol under control
- Wear sunglasses outdoors to block UV and blue light that may cause eye damage.

## **Will changing eyeglasses improve my vision?**

Updating eyeglasses may improve your vision. Your Optician may be able to help you with a visual aid to assist you with reading.

## **Is there a limit to the number of injections I can have?**

We will continue to offer injections as long as they are effective in helping to control the progression of Wet AMD and you as a patient wish to and are able to continue on the programme of injections.

## **Should I put my eye drops in before attending for injection?**

Put your eye drops in as usual before attending clinic (do not use any gel medication you have been prescribed).

## **Will it hurt?**

You may experience some discomfort but local anaesthetic is used to minimise this.

## **What are the risks with these injections?**

As with any medical procedure, there is a small risk of complications following anti-VEGF treatment. Most complications that might occur are from the injection itself, rather than the drug. For most patients, the benefit of the treatment outweighs the small risk of injection injury.

For a list of rare and common side effects of the drugs, please see the individual drug patient information leaflets.

The following are the major potential risks and side effects of anti-VEGF injections, but this is not a complete list of all risks. These risks are all rare. Significant loss of vision due to this treatment is very uncommon.

- Serious eye infection (one in 2,000 cases)
- Detached retina
- Increase in eye pressure
- Blood clots and bleeding in the eye
- Inflammation inside the eye
- Cataract

## **Will I see the needle?**

Prior to administering the injection, the patient is directed to look away so it is very unlikely you will see the needle.



## **How long will it take?**

The injection process takes approximately 10 minutes. However, the time you are in the clinic may be up to one hour.

## **I have been prescribed injections to both eyes, can I have the injections on the same day?**

If you choose to have both eyes treated during the same appointment it may be advisable to have a friend or family member accompany you home.

## **Who will administer the injection?**

These injections will be given either by a registered nurse who has undergone specialist training or a doctor.

## **Can I plan my holiday?**

We advise you not to fly for 24 hours after your injection. If you are planning holidays whilst having treatment it is advisable that you remain within the country for 3 to 4 days after the procedure. It is important that you try and keep to the treatment schedule if possible.

## **Can I go swimming after my injection?**

We advise that you refrain from swimming for 4 days after your injection to minimise the risks of possible infection.

## **What if I cannot attend or miss my appointment or treatment?**

If you cannot attend or miss your appointment you should phone the Macular Clinic that you attend on the number below.

## **What should I do if I am unwell or have been in hospital?**

Contact the Macular Clinic on:

**PPAEP - 0131 536 1373**  
**SJH OPD1 - 01506 524286**

Please have up-to-date information regarding your medical condition available. This will allow the Clinic staff to reschedule your appointment appropriately.

### **Important Note**

If you have suffered a stroke or heart attack within the last 3 months, then it would be necessary to postpone treatment. Injections will start again after a discussion with your care team.

## Things to remember when you attend all Eye clinics

1. Note down details of any problems you are experiencing with your eyes for discussion during your appointment.
2. List any new medications you have been prescribed since your last appointment, **particularly any antibiotics you are currently taking for recently diagnosed infection. If you are currently taking antibiotics your injection will be postponed and rescheduled.**
3. It is important to discuss with nursing staff if you have any ongoing ulcers or open wounds as this may affect your suitability for injection.
4. It may help to have a family member or friend to accompany you, especially if your pupils have been dilated.
5. If you have attended an Optician appointment since your last PAEP Macular Clinic visit you should bring a copy of the report with you.

# **Your Support**

## **1. Family and Friends**

They can support you both physically and mentally. They can chat to you about your problems and accompany you or bring you to the clinic. This can make life easier.

## **2. Your Healthcare Team**

The Ophthalmologist and nurses within the team are all here to help you. The vision support officers located on the 3rd floor provide a range of services; providing practical everyday help for those who are visually impaired.

## **3. Your GP**

Your GP can provide support to you if you feel you are feeling overwhelmed by your diagnosis.

## **4. Eye Clinic Support Service**

This is a service that is provided by the Royal National Institute of Blind People (RNIB) and is based within the Eye Pavilion. They offer support and advice with anybody living with sight loss.

## **5. [www.macularsociety.org.uk](http://www.macularsociety.org.uk)**

You can view patient stories and video accounts to learn more about living with wet-AMD.

## **6. Other Patients**

You can talk to other patients who have wet-AMD about your experience and theirs.

## **7. Treatment Buddies**

Treatment Buddies support people who are anxious about their injections and offer information and reassurance.

To talk about injections and treatment buddies call the Advice and Information Service at the Macula Society on **0300 303 0111** or email [help@macularsociety.org](mailto:help@macularsociety.org)

## **8. Counselling**

Sometimes it helps to speak to a professional counsellor, who is trained to listen and will help you talk through your feelings and find ways of dealing with them. Phone **0300 303 0111** or email [help@macularsociety.org](mailto:help@macularsociety.org)

## **9. Telephone Befriending Service**

The Macula Society aims to find you a befriender who shares your interests or experiences, and who understands exactly what it is like to live with a macula condition. For more information please contact the Macula Society.

# The Amsler Grid

## What is an Amsler Grid?

It is a grid of horizontal and vertical lines used to monitor a person's central vision.

## How do I use the Amsler Grid?

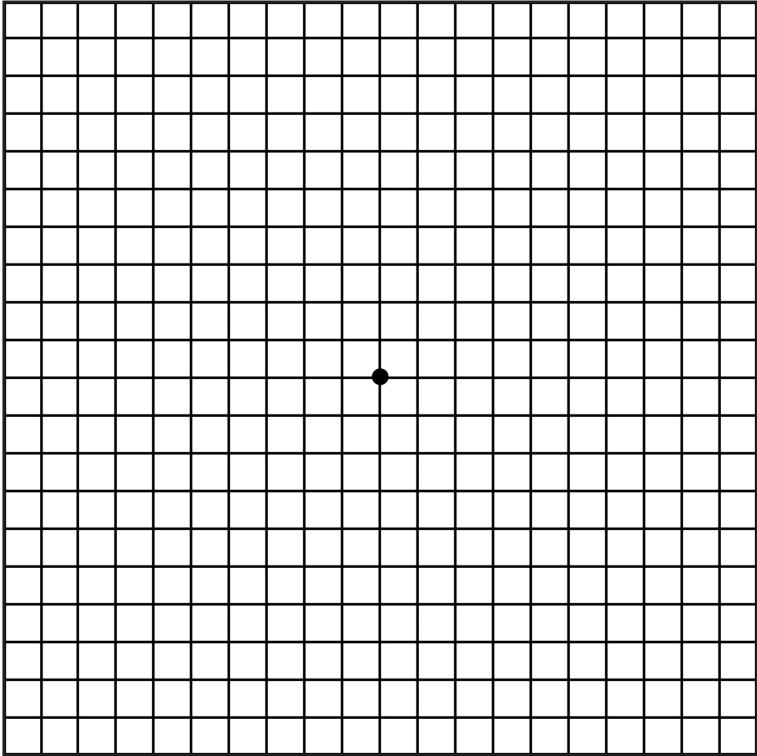
- Hold the grid at your normal reading distance, wearing your reading glasses
- Cover one eye and focus at the dot in the centre of the grid
- Repeat the test with the other eye.

If the lines appear to be **more** wavy, distorted or broken in any way you should contact the macula department within 1 week, as it may mean there has been progression in the macular degeneration.

## How often should I do this test?

Weekly.

# Amsler Grid to Test Your Sight



## **Useful Telephone Numbers**

### **PAEP**

Macula Clinic: **0131 536 1373**

OPD1 St Johns's: **01506 524286**

### **Emergencies, Weekends and Out of Hours**

Ward E2: **0131 536 1172**

### **Triage**

Monday – Friday (08:30 – 16:30): **0131 536 3751**



## **Useful Contact Information/support**

**DVLA**

**0300 790 6801**  
[www.dft.gov.uk/dvla](http://www.dft.gov.uk/dvla)

**Royal College of Ophthalmologists**    **020 7935 0702**  
[www.rcophth.ac.uk](http://www.rcophth.ac.uk)

**Eye Clinic Support Service (PAEP)**    **0131 536 3332**

**Royal National Institute of Blind People (RNIB)**  
**0303 123 9999**  
[www.rnib.org.uk](http://www.rnib.org.uk)

**Macular Society**

**0300 3030 111**  
[www.macularsociety.org](http://www.macularsociety.org)





**Notes:**

**Notes:**

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# Feedback

If you would like to let us know what you think of our service good or bad please feel free to contact us.

You can either use the suggestion boxes in the hospitals

Visit our website -

**<https://www.nhsllothian.scot.nhs.uk/YourRights/ComplimentsConcernsComplaints>**

Send an email -

**[feedback@nhsllothian.scot.nhs.uk](mailto:feedback@nhsllothian.scot.nhs.uk)**

Write a letter -

**NHS Lothian Patient Experience Team  
WaverleyGate  
2 - 4 Waterloo Place  
Edinburgh  
EH1 3EG**

Give us a ring -

**Telephone: 0131 536 3370**

**If you experience increasing pain or blurring of vision after your injection you should contact:**

**Working hours 8.30 - 4.30**

- **Triage at PAEP 0131 536 3751**
- **OPD1 SJH 01506 54286**

**Outwith working hours**

- **E2 PAEP 0131 536 1172**

**Department of Ophthalmology  
The Princess Alexandra Eye Pavilion  
Chalmers Street,  
Edinburgh,  
EH3 9HA**

**Department of Ophthalmology  
OPD1 St John's Hospital  
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EH54 6PP**

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