# Patient Information Leaflet



# Guernsey Department of Ophthalmology

Your Guide to Treatment for Macular degeneration Retinal Vein Occlusions Diabetic Macular oedema



THE MEDICAL SPECIALIST GROUP LLP P.O. Box 113, Alexandra House, Les Frieteaux, St Martin's Guernsey, GY1 3EX. Telephone 238565, Facsimile 237782

The retina and central part called the "macula" at the back of the eye records images focused through the eyeball like the film in an old fashioned camera. If the retina is damaged then images appear blurry and distorted.

Macular degeneration and circulation problems (diabetes) in the back of the eye can damage the retina and cause permanent sight problems which can affect reading, recognising faces and the ability to drive safely.

The opticians in Guernsey can carry out sight checks and will be able to pick up any problems with the back of the eye. It is advisable that people have regular sight checks every 2 years or so with their optician to check the eyes are healthy.

# What is age-related macular degeneration?

This is the most common cause of poor vision in people over 60 in UK. About 270 people a year in Guernsey are newly diagnosed with this. Most people with macular degeneration keep normal peripheral vision, this means they can find their way around but lose detailed vision. It is extremely rare for all the sight to be lost with AMD

The most common type of macular degeneration is called "dry AMD" The optician will advise your GP to prescribe you Vitamins for this VIT EYES II capsules are taken by mouth; one capsule twice a day The dry AMD is usually slowly progressive affecting central vision Your optician is able to monitor this condition

The less common type of macular degeneration is called "wet AMD" About 30 new cases are diagnosed in Guernsey each year Wet AMD can develop rapidly and cause serious central sight problems If it is picked up early it can now be treated with special eye injections This type of AMD is referred to the Eye Clinic at the MSG

# What causes macular degeneration?

Age is a major factor. It is more common in older people Smoking is a big risk especially when there is a family history of AMD Poor diet may be a factor. Greens such as kale, and spinach may help prevent AMD Alcohol has been suggested as a predisposing factor.. Exposure to ultraviolet light may be linked to AMD. Wearing UV protective sun glasses is recommended

# Why is it called 'wet' AMD?

This is a description of what the ophthalmologist sees when looking inside your eyes at the retina and not how your eyes feel.

There is no sensation of watery eyes, in fact the condition is painless

Sight loss occurs when abnormal new blood vessels grow behind the retina. These are delicate and leak allowing fluid into the retina.

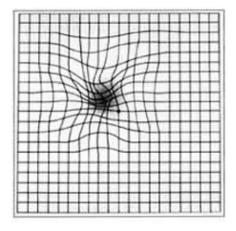
The fluid affects the macula, so that central vision can become distorted and blurry for near and distance vision.

#### NORMAL VISION



VISION IN AMD- WITH LOSS OF CENTRAL VISION





#### WHEN LOOKING AT A SQUARE GRID DISTORTION IS NOTICED in AMD

#### What happens if I have suspected AMD or eye problem?

The optician will advise you to have a special OCT scan.

The OCT is a special 3D photograph of the retina

The Opticians will have to charge £20 -35 for this special scan

The cost of the scan is not covered by the States Contract

The optician will send the scan and their report to the Eye department

At the Eye department the Eye Specialist (Ophthalmologist) will look at the scan and decide if you need to be seen urgently or if your own optician can monitor your eyes and recommend you the Vitamin capsules (VITEYES II)

If you have possible Wet AMD you will be sent an appointment to the Eye clinic at Mill House at the Medical Specialist Group

Please come to the appointment with a friend or relative and they are welcome to stay with you during your consultation

**Do not drive** yourself to the appointment as the vision will be more blurry afterwards

Bring an up to date list of your medication and known allergies Bring your current reading and distance glasses

Treatment may not be possible if you have had a stroke or heart attack within the last six months

Treatment may not be possible if you have uncontrolled angina or uncontrolled high blood pressure

# What happens at my visit to the Eye clinic at Mill House?

#### Check in at the reception desk; You will have a series of tests with the nurses

An eyesight test with your glasses Eye drops to widen your pupils OCT scan Photographs of your retina

### Fluorescein angiogram

on your first visit may be needed

This involves an injection of yellow dye into your arm

You will need to sign a consent form before the Fluorescein dye injection test.

One of the nurses will place a small needle in the back of the hand

A small amount of yellow dye is injected into the needle

A series of flash photographs of the back of the eye are then taken as the dye travels through the blood vessels

The test takes about 10-15 minutes

You can take your normal medication and eat and drink as normal beforehand

The dye may temporarily change the colour of your urine for 1-2 days

The dye may tinge your skin a mild yellow colour for 1-2 days

#### SIDE EFFECTS OF THIS TREATMENT

Blurring of vision

Dazzle from the flash camera

A few patients may feel queasy, faint or short of breath or vomit

More uncommonly an itchy skin rash could develop (treat with antihistamines)

Very rarely a severe allergic reaction and circulation collapse could occur

It is advisable that you remain in the department for 30 minutes after the test

# NOTIFY THE NURSE / DOCTOR IF YOU ARE ALLERGIC TO THIS DYE

#### The ophthalmologist will check the scans then see you and check your eyes too

If there is significant fluid in the retina this is confirmed as wet AMD

You will decide if you want a course of injections

You will need to sign a consent form if you agree to have treatment

You can always change your mind before or later during the treatment

#### You will be booked for a course of eye injections in a week or so

Follow up visits and further injections may be needed

The injections and visits may be needed every month

Your response to treatment will be measured

If the treatment is unsuccessful then you will be advised to stop

# **Is** my injection treatment covered if I have a Social security number?

The States Contract Scheme will pay for NEW patients from 1/4/201

2 years of treatment for New AMD patients

3 years of treatment for New VEIN OCCLUSION patients

3 years of treatment for New DIABETIC MACULAR OEDEMA patients

Patients who are already receiving AMD treatment <u>beyond</u> 2 years on 1<sup>st</sup> April 2014 will still be able to have monitoring and further injections as required

Patients who are already receiving AMD treatment within 2 years on 1st April 2014 will only be entitled to 2 years of treatment

The service will formally be reviewed after 1/5/2015 in accordance with new guidelines

#### **Retinal Vein Occlusions**

There can be a blocked blood vessel (retinal vein) in the retina causing haemorrhages in the retina, fluid leakage and blurred vision

This can be due to high blood pressure and high cholesterol Occasionally other medical conditions cause retinal vein occlusions Blood tests and investigations are required

Please see your GP to organise the following (RCOphth recommendations)
FBC / ESR / Urea & Electrolytes / Creatinine / TFT / Fasting Blood Glucose / Fasting
Cholesterol / Fasting lipids / Plasma protein Electrophoresis / ECG

#### Also for patients under 50

Thrombophilia screen / Anti cardiolipin antibody / Lupus anticoagulant / CRP / Serum ACE

Auto-antibodies; rheumatoid factor / Antinuclear/ Anti –DNA / ANCA / CXR / Fasting homocystine level

#### Treatment

Treatment is similar for AMD patients with Avastin injections and monitoring with OCT scans but not as frequently and for up to 3 years is covered by the States Contract Sometimes a steroid injection is helpful either with **Triamcinalone** which is un-li cenced or with **Ozurdex implant** which is licensed but only available privately

#### Diabetic Macular Oedema

In some diabetic patients there is poor circulation in the retina causing fluid in the macula this is called macular oedema and this results in poor vision.

Sometimes laser treatment can be helpful for mild diabetic problems
For some patients with significant amounts of fluid then Avastin injections are beneficial
On average 4 injections are required a year for 3 years for Macular oedema
Sometimes the blood supply is too poor in the retina and no treatment is possible

It is important that diabetic control is well regulated as well as blood pressure and cholesterol levels, the GP will be able to advise you or the diabetic clinic if you are under their care.

# How do the injections work?

The aim is to stabilise and, when possible, improve vision.

Once your vision becomes stable the injections will be stopped but the monitoring will continue on a regular basis

If your vision continues to deteriorate despite monthly injections the treatment will be stopped.

The injection is into the eyeball and sounds worse than it really is.

The treatment will take place in a clean room

The injections contain an antibody to stop the leaky retinal blood vessels and allow the retina to work better

# What is in the injections?

The injections contain Bevacimuzab or "AVASTIN"

This contains an antibody against blood vessel growth factor (anti-VEGF)

This antibody has been used and is licenced originally for the treatment of bowel cancer It is not licenced for use in the eye but it is very closely related to Ranibizumab

"LUCENTIS" which is licenced for the treatment of AMD and Retinal Vein Occlusions and diabetic macular oedema.

More recently a newer drug Aflibercept "EYELEA" has also been licenced for AMD There are large scale trials which have compared Avastin and Lucentis for AMD The trial results show comparable treatment effect and safety profiles for patients at 2 years

"Avastin" is much cheaper than "Lucentis" and is shown to be very cost effective The use of Avastin for eye conditions is known as "off label" treatment

**HSSD have commissioned Avastin injections for the States Contract Patients** Guernsey patients have been having Avastin injections since 2007 in Southampton Worldwide patients have been having Avastin injections since 2007

If patients would prefer to have Lucentis or the newer drug Eyelea this is only available as a private patient; the charges are listed on the next page for treatment and investigations

FEE

New patient consultation	Code	£190	
Follow up consultation	Code		£130
OCT scan	Code C873		NO PRICE IN
WPA			
Fluorescein angiography & photography Code C8650		£115	
Ocular photography as sole proceed	dure Code C8652	£110	
Intravitreal injection	Code C7940		£350
Local anaesthetic	Code AC100	£110	
"Avastin" Bevacizumab drug cost			£100?
"Lucentis" Ranibizumab drug cost			£800 ?
"Eyelea" Aflibercept drug cost			£800 ?

# How are the injections performed?

The forehead above the affected eye is marked with an arrow The eye is numbed with anaesthetic drops and cleaned with IODINE The eyelids are held open with a gentle metal clip Your face covered by a light drape to keep the area very clean The injection only takes a few minutes and is usually painless

# After the injection

Antibiotic eve drops need to be taken:

CHLORAMPHENICOL drops for 5 days afterwards 4 x a day to the treated eye

This is important to prevent infection

The eye pressure may go up for a few hours and extra drops may be needed

You will need to book another appointment a month later

Afterwards your eye will be blood shot this can last 2 weeks

The eye will feel gritty and a slight ache for 2 days

You may see floaters in the vision from the injection

You may see swirls of light immediately after the injection

If your vision becomes more blurred, very painful and your eye more red 2-5 days after the injection you should contact either

the eye clinic 238565 URGENTLY from 0830-1730

b) the duty Ophthalmologist via the PEH switchboard after hours 725241

# What are the complications of treatment?

The risks are small but you need to be aware of these before you start treatment and before you sign the consent form. If you have any questions you must ask the doctor before you sign the form.

You must notify the doctor before the treatment if the eye is red and sticky

# These risks can occur commonly in about 1 in 10 people

Decreased sharpness of vision (retinal pigment epithelium tear or detachment)

Disturbed vision

Bleeding inside the eye (Vitreous haemorrhage)

Clouding of the lens

Damage to the front laver of the eve (corneal trauma)

Increase in eye pressure (raised intraocular pressure) Moving spots or swirls in the vision (vitreous floaters or vitreous detachment)

(cataract)

Pain at the site of the injection or gritty sensation

Increased production of tears (lacrimation) Swelling of the eye lid (evelid oedema)

Bleeding on the white of the eye (subconjunctival haemorrhage)

This is more common if you take blood thinners General redness of the eye (hyperaemia)

# Uncommon side effects may affect up to 1 in 100 people

Allergic reactions (hypersensitivity)

Severe inflammation inside the eye (uveitis)

Damage to the retina layers needing surgery (retinal tear, retinal detachment)

Persistent irritation of the eye

# Rare side effects which may affect up to 1 in 1,000 people

Severe eye infection or inflammation (Endophthalmitis)

# There can also be small risks to your general health

You should not have this treatment if pregnant or breastfeeding Mild increase in blood pressure Slight increase in risk of stroke 1per 1800 patients

Slight increase in heart attacks

#### How successful is the treatment?

There is an improvement in vision in about 22% of patients Stabilised vision for about 65% of patients The vision becomes worse and may be stopped in about 12%

Smokers and patients with high blood pressure are likely to get poor results

For the small number of patients whose vision worsens and they have to stop treatment they will be advised to contact the Guernsey Blind Association for support and advice on how to manage with poor sight. They can be formally registered as having a sight problem. It is extremely distressing to lose sight and feel depressed with this, so having help is essential in learning to cope and adapt successfully to sight problems. The Guernsey Blind have specially trained support staff who can help you.

#### **Comments**

This is a new service and there will invariably be issues with starting this and we would appreciate your understanding if you incur any delays. As many of you have experienced treatment already in Southampton you may have some ideas on how we can improve our service for you.

Any feedback on the AMD service so that we can improve and develop this further, o
complaints about your treatment should be addressed
to

#### **Contacts**

#### **Ophthalmology Dept**

The Medical Specialist Group LLP Mill House Les Frieteaux St Martins GY1 3EX

**Tel: 238565** Fax: 237782

The Macular Society

PO Box 1870 Andover SP10 9AD

Tel: 01264 350 551 www.macularsociety.org info@macularsociety.org

#### **RNIB Helpline**

Tel: 0845 766 9999 www.rnib.org.uk helpline@rnib.org.uk

#### **Guernsey Blind Association**

[Debbie and Paula] LE Four Cabot Centre St Andrews GY6 8XE Tel: 236 933 gba@guernsey.net

Office open Monday-Friday 9.15am - 12.15pm.