

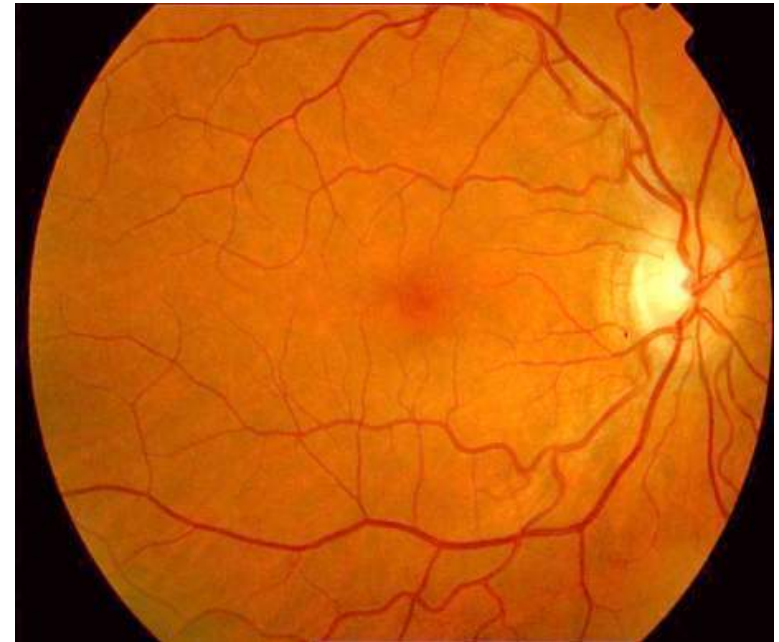
## Leaflet 1

### Information on age-related macular degeneration

#### What is age-related macular degeneration?

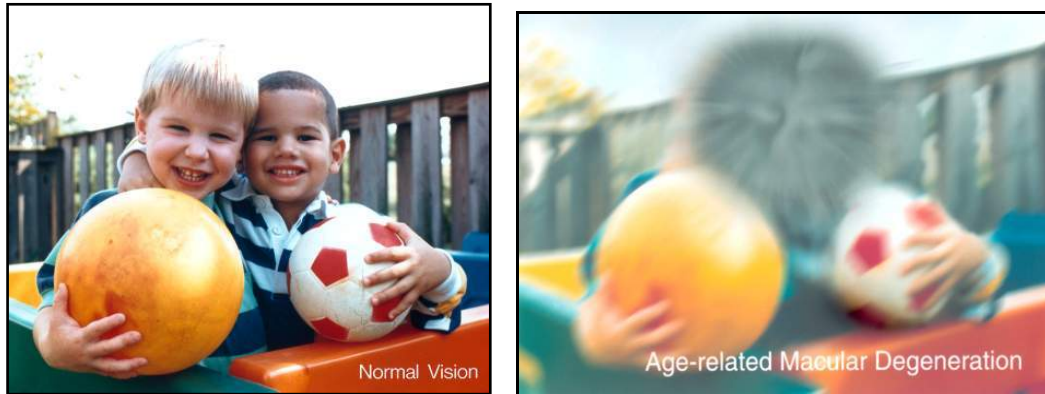
Age-related Macular Degeneration or AMD is a condition that typically affects patients over the age of 50. It becomes increasingly common as patients grow older and at the age of 75, one in three people have some signs of macular degeneration in their eyes. This figure increases to one in two of the general population by age 85. It is, therefore, a very common problem for many people as they grow older.

AMD affects the back of the eye and in particular the tissue that senses light. This tissue is called the retina and it is like a photographic film in a camera.



A normal retina  
(Photo credit: National Eye Institute, National Institutes of Health)

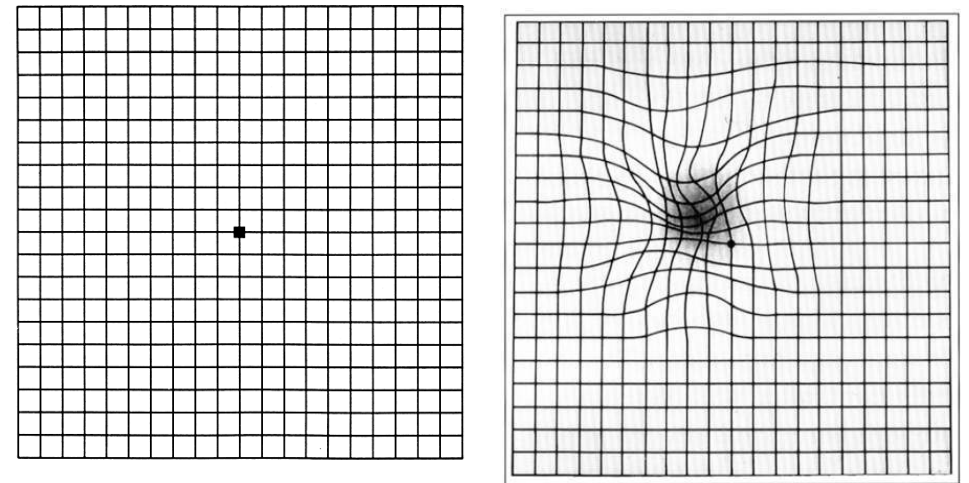
Macular degeneration affects the central part of the retina and so central vision alone is affected.



Normal vision and the same picture as seen by somebody affected by severe macular degeneration (Photo credit: National Eye Institute, National Institutes of Health)

In the early stages patients may notice decreased vision or distortion of vision. Distortion of vision is particularly a problem for patients with wet AMD so objects that

should appear straight, such as the side of the door, have a kink in them.



An Amsler Grid of straight lines and how it might appear to somebody with wet macular degeneration – the lines appear distorted and kinked. (Photo credit: National Eye Institute, National Institutes of Health)

Over a period of time, vision can become more severely affected causing a patient to

have difficulty reading a visual acuity chart. Most patients, however, retain their peripheral sight. Some central vision may also be maintained

The early forms of age-related macular degeneration usually cause the retina to become thinner and this is called dry macular degeneration. This results in a reduction in the number of cells that sense light in the centre of the eye. Another analogy is to think of a carpet that has bare patches. When an eye doctor looks into the eyes of a patient with early macular degeneration bare patches are seen in the retina. This is called dry macular degeneration.

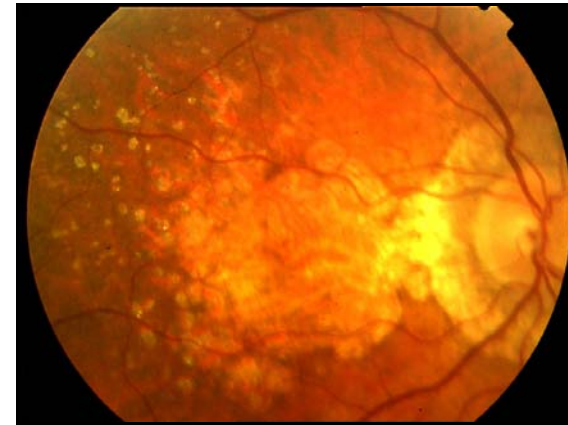


Photo of Dry macular degeneration  
(Photo credit: National Eye Institute, National Institutes of Health)

In approximately 1 in 10 people with AMD an additional complication occurs which is called wet macular degeneration. In wet macular degeneration blood vessels grow into the retinal tissue from the deeper blood vessel layers at the back of the eye. This is similar to weeds coming through cracks in the pavement. These new blood vessels

tend to leak and bleed fluid and eventually they form scar tissue in the back of the eye. Vision can, therefore, be very rapidly affected with a dramatic loss of central vision. If wet macular degeneration is treated quickly this process of blood vessel growth can be stopped and the patients' vision can be restored in some cases.

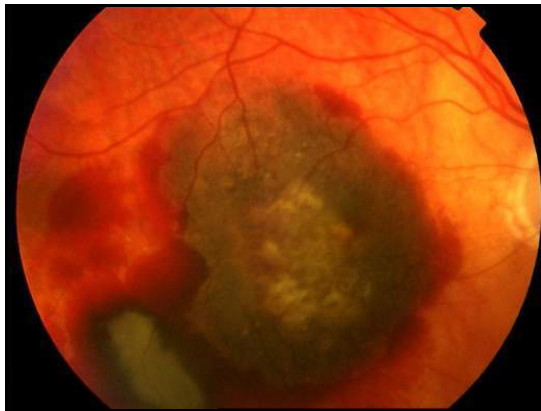


Photo of wet macular degeneration

(Photo credit: National Eye Institute, National Institutes of Health)

## What causes macular degeneration?

You are more likely to develop macular degeneration as you get older. The main preventable risk factor for disease progression is cigarette smoking which increases the risk four fold. In some patients with a particular genetic background smoking increases their risk twenty fold. The most important thing to do if you are told that you suffer from macular degeneration is to reduce or stop smoking.

Research shows that faulty genes also contribute to the risk of developing this disease.

Scientists can now find a genetic risk factor in approximately 90% of patients. Ongoing research is directed at developing new

treatments based on the understanding that has come from discovering these genetic risk factors.



Some of the researchers in the Gift of Sight Eye Research Laboratory, Southampton General Hospital

## Should I have genetic testing?

Treatment possibilities for AMD are not presently chosen according to your genetic makeup and therefore we do not recommend genetic testing at this time. In the future however, as new treatments are devised our recommendation may change. Genetic testing for AMD is not available on the NHS.

## What treatments are available?

In patients, who have not smoked for at least six months it is feasible to recommend a mixture of vitamins to prevent further progression of age-related macular degeneration.

In one large study patients with early-to-moderate signs of age-related macular degeneration who took high-dose vitamins saw their risk of further progression reduced by 25%. These vitamins are a mixture of vitamin A, C and E as well as copper and zinc. There are several commercial preparations that contain the same vitamins which were found to be effective in this large-scale clinical study.

These include Viteyes Original vitamins. These can be prescribed in some instances by general practitioners or are available to buy from chemist shops or online at [www.viteyes.co.uk](http://www.viteyes.co.uk).

An alternative preparation is made by a company called Bausch & Lomb and their

preparation is called PreserVision tablets. They too can be prescribed in some instances by general practitioners or are available to buy from chemist shops or online.

These supplements both contain the same mixture of vitamins that have successfully been shown to reduce the risk of progression of macular degeneration. They should not be taken with any other vitamin supplements because of the high doses of vitamins contained within these preparations. In addition, they should not be taken by smokers because there is possibly an increased risk of lung cancer in people who take vitamin A and who also smoke.

## Should I take Lutein?

**Lutein** is one of over 600 known naturally occurring [carotenoids](#). Found in [green leafy vegetables](#) such as [spinach](#) and [kale](#), lutein is employed by organisms as an [antioxidant](#) and for blue light absorption. While there is some evidence that Lutein may be helpful in preventing macular degeneration, this has not as yet been confirmed by a large-scale clinical trial. Therefore, scientifically we cannot recommend taking Lutein at this time. As further studies are undertaken our advice may change.

## How do I know if I have wet macular degeneration?

Symptoms of possible wet macular degeneration include:

- 1) a sudden change in your vision
- 2) blurred central vision
- 3) distorted vision eg where straight lines such as the side of a door become kinked

If you have any of these symptoms we would recommend that you attend an Eye Casualty Department as a matter of urgency to exclude the development of wet macular degeneration.

If wet macular degeneration is confirmed it is important that you are seen ideally within two to three weeks at a specialist clinic where appropriate treatment will be recommended. In most cases this involves a series of injections into the eye, which allows an eye specialist to deliver drugs that can switch off the blood vessel growth. In large-scale clinical trials it has been shown that this approach can improve vision in 30% of patients and stabilised vision in 90% of patients. It is not clear how many treatments patients may need but typically most patients need at least three injections (one a month) and this may be supplemented by further injections as required. There are several new treatments for wet macular degeneration being

developed and there may also be opportunities to participate in clinical trials which are assessing these new treatments. Your ophthalmologist should be able to advise you regarding the feasibility of joining such a trial.

### **What other problems can develop with macular degeneration?**

In some patients, particularly those who have severe loss of vision in both eyes, a complication may develop where they see things that are not actually there. These visual hallucinations are called Charles Bonnet syndrome. This can vary from seeing kaleidoscopic colours to seeing faces or people who are not actually there, which

some patients might find disturbing. Only a small percentage of patients develop this complication but it is important to be aware of it.

## What else can be done for my condition?

In many cases low vision aids, or magnifiers, can help patients to see more. This may be something as simple as a bright reading light, particularly a Daylight or fluorescent type lamp, or by obtaining a magnifying glass that also has a built-in light. There are specialist clinics that can provide help with low vision aids. In addition, there are sophisticated electronic equipment that can project images onto

either a TV screen or computer monitor and these aids can be helpful in some situations.

## Other sources of help

There are several patient self-help groups that can provide additional help and advice.

Self Help Group	Telephone Number	Website
Vision Enhancers	0800 112 3691	<a href="http://www.visionenhancers.co.uk">www.visionenhancers.co.uk</a>
Open Sight	023 8064 1244	<a href="http://www.opensight.org.uk">www.opensight.org.uk</a>
The Macular Disease Society	0845 241 2041 or 01264 350559	<a href="http://www.maculardisease.org">www.maculardisease.org</a>

Royal National Institute for the Blind	0303 123 9999	<a href="http://www.rnib.org.uk">www.rnib.org.uk</a>
--	------------------	--

Open Sight can also offer access to a low vision room where you can try various low visual magnification aids.

Finally, the Gift of Sight Appeal is a local charity supporting ongoing research into developing better treatments for age-related macular degeneration here in Southampton. We are very appreciative of the support they provide us and copies of our information leaflets are provided on their website [www.giftofsight.org.uk](http://www.giftofsight.org.uk). Tel. 023 8059 9073.

## Should you be registered as visually impaired?

Your doctor may recommend that you be registered as partially or severely visually impaired. Whilst many people do not like being registered in this way there can be advantages. Firstly, the government uses registration as a form of anonymous census to alert them as to how severe a problem such as macular degeneration has become. This is extremely useful when trying to obtain further resources to treat this problem. Secondly, and only if you would like this, it can be useful to alert the Social Services so that they can provide further domestic assistance. In addition, if you need any other sort of support from Social

Services, being registered as visually impaired is helpful in supporting your case. There may be additional financial benefits such as concessions in rail tickets or a reduction in taxes if you are registered as visually impaired.

All that is required to become registered is your signature on a simple form. If you are registered as visually impaired you are automatically not allowed to drive. However, if your doctor is suggesting this you do not have sufficient vision to enable you to drive legally.

### **Where can I learn about possible new treatments?**

The Gift of Sight Appeal has information regarding ongoing research on their website [www.giftofsight.org.uk](http://www.giftofsight.org.uk). Potential new treatments include types of drugs that have been developed as a result of our new understanding of AMD derived from genetic studies and in the long term, perhaps in the next five to ten years, it may be possible to offer some form of stem cell therapies. However, these are not imminent. Artificial eyes, or Bionic eyes as they are sometimes called, are also in the developmental stage but are not routinely clinically useful at this time.

### **Summary**

Age-related macular degeneration is a condition that affects many people as they

get older. There have been significant improvements in treatment over the last five years and, because of this, many people can maintain their sight. Ongoing research should lead to further improvement in treatment in the near future.

