**AMD Day FAQ**

**What demographics are most at risk for AMD?**

AMD is complex disease and an individuals’ chance of the developing the condition is influenced by a number of factors including age, genetics, diet and lifestyle. Whilst there are a number of known risk factors, which appear to be more common in people diagnosed with AMD, having one of these is by no means a guarantee that you will develop AMD. Likewise, there is no guarantee you won’t get AMD if you don’t meet all of these criteria. From a number of studies we know the risk of developing AMD appears to be higher in those:

* **Over the age of 50** – AMD is a condition related to aging. The likelihood of developing AMD increases as we age
* **With a family history of AMD** – your genes (i.e. the instructions in your DNA that make you who you are) play an important part in determining your risk of developing many conditions including AMD. Your genes are passed onto you from your parents, who received their genes from their parents. So, if your family have a gene that contributes to AMD it is possible for it to be passed on
* **Of Caucasian (white) origin** – a number of scientific studies have shown people of Caucasian origin have a high risk of developing AMD. There is also evidence of a higher risk of AMD in those of Chinese origin and increasing rates of AMD in Japan have been reported
* **Who smoke** – the link between smoking and macular disease is well established. People who smoke are four times more likely to develop macular degeneration and this increases to twenty times if there is macular degeneration in the family. More information on the link between smoking and macular disease can be found at the smoking campaign website of the Macular Society – [http://www.is-it-real.org](http://www.is-it-real.org/)
* **With an unhealthy diet / high cholesterol** – diet is known to play an important part in your overall health. High fat and cholesterol levels can result in fatty deposits in the eye, which may increase the risk for AMD. There is also evidence to suggest that people with diets low in fresh fruit and vegetables and in fish may lack important nutrients that can protect vision
* **Who are overweight / inactive** – higher incidences of AMD have been reported for overweight and inactive people
* **Who have cardiovascular disease** – there are some markers for cardiovascular disease that have also been associated with AMD. Lifestyle changes to improve heart health are likely to be beneficial for eye health too
* **Who are women** – there is some evidence to suggest that AMD is more likely to occur in older women, but other risks factors are likely to be more influential

**# # #**

**What can be done for AMD today?**

Whilst AMD is driven by aging and your own genes, which we can’t do anything for, should you be diagnosed with AMD there are a number of simple things you can do to help maintain and monitor your own eye health:

* **Stop smoking** – smoking helps AMD progress. Speak to your GP about quitting and what support is available
* **Improve your diet and level of activity** – being more active, increasing the number of fresh fruits, vegetables and fish in your diet and reducing high cholesterol and fatty foods in your diet are good for overall health and are likely to be good for eye health too
* **Wear sunglasses outside**– ultra-violet light and blue light from the sun (both of which are invisible to us) are particularly damaging to the eyes. When out in the sun it is advisable to wear sunglasses. Yellow, amber, and brown lenses provide the most protection and can also help with contrast vision. Speak to you healthcare professional about getting the right, custom sunglasses that will be of most benefit to you
* **Regularly check your own vision** – an Amsler Grid (<http://www.macularsociety.org/How-we-help/Information-leaflets>) is an easy way to monitor your vision and check for distortions and changes in your vision. If your vision appears to be changing you should make an appointment to see your healthcare professional straight away
* **Continue to go to regular optician and ophthalmology appointments** – it is important to continue to monitor the eye; attending regular appointments increases the likelihood of detecting early changes that can be addressed

Unfortunately AMD cannot be cured. Currently there are no proven treatments for dry AMD. The steps above are your most prudent course of action to help reduce progression of your AMD and to monitor for the possible development of wet AMD.

For people with wet AMD we now have two licensed treatments available that target vascular endothelial growth factor (VEGF), the substance responsible for the growth of fragile blood vessels in the eye that can leak and cause macular degeneration. These treatments can delay the progression of wet AMD for many people. Your healthcare professional will advise you if these treatments are suitable for you and when would be best to start receiving treatment to get the most benefit.

There is a clear need for additional treatment options for AMD – gene and cell therapies are just one approach currently being investigated for this purpose.

**Is there any research into food / diets in relation to eye health, especially inflammation?**

AMD is one of a number of eye conditions related to inflammation. Most notably for AMD there have been two major, national studies from the United States of America looking into the impact of nutritional supplements on the progression of inflammatory eye disease – the **A**ge-**R**elated **E**ye **D**isease **S**tudy (**AREDS**), the first one in 2001 and then a further study called **AREDS2** in 2012.

The AREDS study tested whether a daily, oral supplement containing high doses of vitamin C, vitamin E, zinc, copper and beta-carotene (vitamin A) could help prevent or slow AMD progression. In people at risk of developing advanced AMD these supplements reduced disease progression by 25% at five years.

In 2012 the AREDS2 study was initiated to determine if this formula could be improved upon by adding in omega-3 fatty acids (important for healthy photoreceptors), by reducing the amount of zinc (which is associated with urinary tract problems) or by replacing beta-carotene (which has been associated with an increased risk of lung cancer in people with a history of smoking) with lutein and zeaxanthin. AREDS2 demonstrated that:

* Lutein and zeaxanthin (plant pigments which are found in the eye and may help protect sight) further reduce progression to advanced AMD by 10% at 5 years
* Reducing the amount of zinc had no negative effects
* Adding in omega-3 didn’t offer any additional benefits

**So what have the AREDS / AREDS2 trials shown us?**

It is important to note that **these formulations cannot prevent AMD nor stop its progression to more advanced forms.** AMD is largely driven by aging and your genetics which diet can’t influence. However, there is some evidence to support that diet may help reduce progression of advanced AMD in some people but this is likely to be dependent on the individual, their lifestyle and the natural progression of their disease.

The AREDS/AREDS2 formulations were most effective in people with diets low in some of these nutrients, which are also found in a number of fresh fruits, vegetables and fish.

The AREDS’ trials have also showed that these dietary supplements cannot compensate for the impact of smoking on AMD so it is advisable to stop smoking altogether.

Whilst there are a number of other food supplements, containing other nutrients available to buy, only those nutrients tested in the AREDS and AREDS2 formulations have been studied in controlled clinical trials, specifically for use in people with AMD.

**Before taking a dietary supplement you should consult your healthcare professional to ensure that there are no complications associated with any medications you may be taking or any health concerns that you have.**

You kind find further information on the AREDS’ studies at:

* <https://web.emmes.com/study/areds/>
* <http://www.areds2.org/>
* <http://www.nei.nih.gov/areds2/>

 **# # #**

**How many years between onset and full macular degeneration?**

It is extremely difficult to predict how AMD might progress for the individual. AMD is the result of a combination of factors including a persons’ age, genetics diet and lifestyle all of which differ from person to person.

Whilst we can’t do anything about aging and genetics which are key drivers of AMD, making changes to your diet and lifestyle and taking steps to monitor your own vision and attend eye exams can play an important role in helping to reduce progression of AMD and ensure that changes in your vision are diagnosed and addressed earlier.

 **# # #**

**If only one eye is affected by AMD, is the other eye at risk?**

Unfortunately, having AMD in one eye does mean you are at increased risk of developing AMD in the other eye and so regular monitoring is recommended. See the question on **What can be done for AMD today?** for more information.

**# # #**

**Is there a connection between steroid use and AMD?**

“I have chronic lymphoid leukaemia and 2.5 years ago I had six weeks of steroid treatment, prior to commencing treatment for wet AMD. Would the steroid treatment have had any effect on my eyes?”

**AMD Day Attendee**

AMD is the result of a combination of factors including a persons age, genetics diet and lifestyle. No association between steroid treatment and wet (or dry) AMD has been reported to date.

**# # #**

**Is there a relationship between wearing contact lenses and the causes of wet AMD?**

“As a contact lens wearer for many years I was told to only wear them for three or four days week as I was producing extra blood vessels in my eyes, is there a connection?”

**AMD Day Attendee**

**No**, wearing contact lenses would not cause a person to develop wet (or dry) AMD. AMD is the result of a combination of factors including a persons age, genetics diet and lifestyle. During a routine eye exam, the detection of abnormal blood vessels growth at the back of the eye, such as that associated with wet AMD, would be coincidental.

It is important to attend regular eye checks with your optician to ensure that such abnormalities in your eye can be detected earlier and you can be referred to a specialist. Early detection and diagnosis is an important first step in reducing the progression of many diseases including AMD.

**# # #**

**Is there any association between Central Serous Retinopathy and wet AMD?**

No association between Central Serous Retinopathy (CSR) and wet (or dry) AMD has been reported to date.

Wet AMD is a progressive and life-long condition that results from the abnormal growth of fragile blood vessels (caused by vascular endothelial growth factor [VEGF]) at the back of the eye that leak, causing blood to collect behind the macular damaging the light sensitive cells and damaging fine, central vision.

CSR on the other hand for many people can be temporary and the majority of people can regain much of their sight without treatment. In CSR tiny breaks between cells cause fluid to leak behind the macular disrupting vision. The exact causes are unknown but the condition has been linked to stress and steroid use.

**# # #**

**Is there any association between oestrogen deficiency and wet AMD?**

An association between levels of oestrogen and wet AMD has been theorised.

Reported incidences of AMD appear to be higher in women than men. One theory for this is that oestrogen may have a role in delaying or stopping the development of AMD making it more likely in older, post-menopausal woman who will naturally have low levels of oestrogen.

There have been a number of studies looking at whether there is a connection between a woman’s oestrogen levels, her use of oestrogen containing contraceptives and / or oestrogen containing hormone replacement therapy and the progression of AMD. To date no conclusive links have been established.

**# # #**

**Can you provide further information on the NHS national questionnaire for eye health?**

In July 2013 the NHS belongs to the people – a call to action was launched. The Call to Action sets out many of the challenges for the NHS in the face of an increasing elderly population with multiple long-term conditions, against a backdrop of financial constraints.

There are several strands to the Call to Action one of which is a focus on improving eye health and the provision of NHS eye health services. It’s estimated that partial sight and blindness in adults costs the UK economy around £22 billion per year. This Call to Action will focus on a more preventative approach to eye health services including early accurate detection by primary care services and effective management in the community.

NHS England wants the public, patients, and professionals to engage with the Call to Action through a survey that will help review the current system to inform and develop a long-term sustainable eye health services plan.

To find out more about the survey go to:

* [**http://www.england.nhs.uk/ourwork/qual-clin-lead/calltoaction/eye-cta/**](http://www.england.nhs.uk/ourwork/qual-clin-lead/calltoaction/eye-cta/)

**Why wasn’t there more time for consultation with clinicians at AMD day?**

The purpose of AMD day was to discuss and ask questions about current research into AMD and in particular gene and stem cell research and the potential to help people with AMD in the future.

Whilst we always strive to answer general enquiries many of our presenters on the day were scientific researchers and not medical professionals and as such unable to offer a medical opinion.

It always advisable that if you have specific questions about your own disease you should discuss these with your own healthcare professional who has a much better idea of your medical history and personal circumstances.

We are aware it is not always possible to get all of your questions answered during a consultation. Many hospitals will have their own patient advice and support organisations who may be able to provide additional support such as PALS at Moorfields ([**http://www.moorfields.nhs.uk/content/patient-advice-and-liaison-service-pals**](http://www.moorfields.nhs.uk/content/patient-advice-and-liaison-service-pals)) and patient organisations such as the Macular Society ([**http://www.macularsociety.org**](http://www.macularsociety.org/)) are another key source of information.

**# # #**

**How can I gain access to / volunteer in a clinical trial?**

**Participation in clinical trials was the theme of one of our posters on AMD day. This poster is available in the poster library section of our AMD day page.**

A clinical trial is research that involves the comparison of one form of treatment to another in either patients or healthy individuals and they are implemented for a number of reasons:

* To determine whether new medicines work as well and as safely as expected.
* To assess if new treatments are safe to use
* To assess if treatments have any associated side effects
* To observe if new treatments are better than the available standard treatment

Unfortunately, being interested in participating doesn’t guarantee a place on a clinical trial. Before you begin researching into clinical trials there are a number of things to be aware of:

* **Enrolment criteria** – to ensure the safety of those participating and to ensure findings are reliable, clinical trials must have strict enrolment criteria. Your past and current medical history, any medications you are taking and even the type or stage at which your condition is at will need to be assessed before you could participate
* **Follow up** – most clinical trials require participants to attend a number of follow up appointments over the course of several years to monitor their progress. It is important to decide if you can give this much time to the trial and to ensure you can attend the treatment centre as and when required
* **You may not be the person getting the new treatment** – depending on the type of clinical trial not everyone enrolled will necessarily get access to a new treatment. Some people enrolled could receive what is called a mock or placebo treatment. Through the trial the identity of who is on the new treatment and who is on the placebo is kept secret. By comparing data from these two sets of people, the effect a new treatment is having can be better assessed
* **Improvement in your condition is not always the goal of a trial** – some trials, particularly those categorised as being a phase I trial are often designed to assess if a treatment can be well tolerated by those receiving it. This means that in those participating we would not necessarily expect to see any improvements. Often improvement is then looked at more closely in the later trials.

If you decide that you would be interested in participating in a clinical trial then there are a number of different ways you might be able to get involved:

* Speak to your healthcare professional they may be aware of clinical trials for your condition
* Speak to a patient group or charity who support research they may have information on clinical trials
* Research online there are a number of databases or registry’s which hold lists of current clinical trials