

Guide to essential care for wet age-related macular degeneration (wet AMD)

Keep this checklist so that you know what care you should have at each stage of your AMD.

1. If a GP or optician suspects you have wet AMD they should fax a referral letter to a specialist doctor at a fast-track macular clinic the same day. You should be told how long you will have to wait and given a number to call if your referral does not come through quickly.
2. An optometrist should not refer you back to your GP as this causes unnecessary delay.
3. You should have an appointment with the specialist ideally within one week of referral and not longer than two weeks.
4. If you need treatment you should receive it within one week of the appointment with the retinal specialist and not longer than two weeks.
5. There are several drugs licensed to treat wet AMD. If you are treated with Lucentis you should start with three injections, each one month apart. The number of injections you have after this will vary.
6. If you are treated with Eylea you should have three injections each one month apart and then injections every eight weeks for the first year. After that your doctor will decide how often you need to be checked. **It is important you are given clear information about your treatment regimen so you feel confident that your next appointment is not forgotten or overlooked by the eye clinic.**
7. If you are offered Avastin you should be told why and that it isn't licensed for use in eyes. In March 2015 the government ruled that the routine use of Avastin for macular diseases was unlawful.

Helpline 0300 3030 111

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8. Whoever diagnoses your macular condition should give you its name, a clear explanation of it and written information in large print for you to take away. You should be told where to find more information and support for people with AMD, such as the Macular Society.

9. If your condition stabilises and you're discharged you should be told how to monitor your vision for changes and how to get a new appointment immediately if your vision deteriorates.

10. You should be advised on how to protect your eyes from uncomfortable glare.

11. You should be given advice on good diet and nutritional supplements to reduce your risk of developing more advanced AMD.

12. If you smoke you should be advised to stop and offered help to stop. Smoking makes wet AMD worse and treatment less effective.

13. If you have problems with everyday tasks and getting about safely, your hospital doctor should refer you to a low vision service or suggest you have an assessment by social care. This should happen before you lose a lot of vision, possibly while you are still receiving treatment. It is easier to learn how to make the most of your sight while it is still good.

14. If your vision worsens you should be given the opportunity to be registered as sight impaired. This gives access to benefits and services.

15. You should be told about the possibility of seeing images, known as Charles Bonnet Syndrome. These visual hallucinations affect many people with sight loss. They are not a sign of a mental illness.

16. You should be offered emotional support or signposted to a service which can help, for example the Macular Society counselling service.

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17. You should have regular eye tests at your optometrist. If you are over 60 or registered as sight impaired this test is free.

Join the Macular Society for regular updates on research into macular disease, new therapies and information on living well with wet AMD.

For more information about AMD contact our Helpline 0300 3030 111

These guidelines are drawn from published NICE guidance and from the Royal College of Ophthalmologists Age-Related Macular Degeneration: Guidelines for Management 2013.

Sources

Royal College of Ophthalmologists

Age-related macular degeneration: Guidelines for Management 2013

National Institute for Health and Care Excellence

TA 155 (Ranibizumab and pegaptanib for the treatment of wet age-related macular degeneration)

TA294 (Aflibercept solution for injection for treating wet age-related macular degeneration)

NHS Choices

Living with low vision

Free eye examinations

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