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 make an urgent referral to a hospital eye clinic, whether or not there is any visual impairment. The referral should normally be made within one working day. Referral to Accident and Emergency is not necessary.

2. You should be told how long you will have to wait for an appointment and given a number to call if your referral does not come through quickly.

3. An optometrist should not refer you back to your GP in cases of wet AMD as this causes unnecessary delay. They may refer to your GP if they detect some other condition.

4. If you need treatment, you should receive it as soon as possible and within 14 days of being referred.

5. There are three drugs available for treating wet AMD, termed anti-VEGF drugs: Lucentis, Eylea and Avastin. All three are clinically effective and safe for use. Lucentis and Eylea are licensed for treatment on the NHS. Avastin is not licensed but may still be used in some circumstances.

6. 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.

7. 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.

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8. If you are offered Avastin you should be told why and that it isn't licensed for use in eyes.

9. It is important that you are given clear information about your treatment schedule so that you feel confident that your next appointment is not forgotten or overlooked by the eye clinic.

10. You should be offered certification of visual impairment as soon as you become eligible.

11. If you need help with everyday tasks your ophthalmologist should consider referring you to low vision services and a group-based rehabilitation programme.

12. If your visual acuity is 6/96 or worse your ophthalmologist should consider anti-VEGF treatment only if a benefit to your overall visual function is expected.

13. If your visual acuity is better than 6/12 your ophthalmologist should be aware that anti-VEGF treatment is clinically effective.

14. Your ophthalmologist should consider switching anti-VEGF treatment if there are practical reasons for doing so, for example, if a different drug can be given in a treatment pattern you prefer.

15. Your ophthalmologist should consider observation without giving anti-VEGF treatment if your disease appears stable.

16. Your ophthalmologist should consider stopping anti-VEGF treatment if the eye develops severe, progressive loss of visual acuity or if the eye develops late AMD with no prospect of functional improvement.

17. You should be actively involved in all decisions about the stopping or switching of treatment.

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18. If you are discharged from hospital services you should be advised to:

- Self-monitor your AMD, having the techniques explained
- Consult your eye-care professional as soon as possible if your vision changes, including: blurred or grey patch in your vision; straight lines appearing distorted; objects appearing smaller than normal.

19. You should continue to attend routine sight-tests with your optometrist.

20. If you are being monitored for late AMD both eyes should be reviewed at your monitoring appointments.

21. Your ophthalmologist should encourage and support you if you are concerned about self-monitoring. If you are not able to self-manage your AMD, monitoring techniques should be discussed with your family members or carers.

22. You should be provided with information in accessible formats to take away at your first appointment, and then when you ask for it covering:

- Information about AMD and how you will be treated, including likely timescales
- Key contact details – for example, who to contact if appointments need to be altered
- Advice about what to do and where to go if vision deteriorates
- Available support (including transport and parking permits)
- Links to local and national support groups.

23. Your ophthalmologist should allow enough time to discuss your concerns and questions about your diagnosis, treatment and prospects for your vision.

24. Your ophthalmologist should promote peer support, particularly for people who are beginning injections treatment, who may be reassured by someone who has previously had the same treatment.

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25. Your ophthalmologist should provide you and your family members or carers (as appropriate), with information that is:

- Available on an ongoing basis
- Relevant to the stage of your condition
- Tailored to your needs
- Delivered in a caring and sensitive fashion. Your ophthalmologist should provide opportunities to discuss:
- What AMD is; how common it is; tests and treatment; types of, and causes of, AMD
- Where your appointment will take place, who will be responsible for your care and expected waiting times for consultations, investigations and treatments
- Stopping smoking and other lifestyle advice
- How AMD may progress and possible complications
- The possibility of developing visual hallucinations associated with your loss of vision (Charles Bonnet syndrome)
- Vision standards for driving
- Who to contact for practical and emotional support
- The benefits of being registered as sight impaired or severely sight impaired
- Other sources of information available

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

For more information about all aspects of AMD contact our Advice and Information Service 0300 3030 111

These guidelines are drawn from the National Institute for Health and Care Excellence Age-related macular degeneration: diagnosis and management clinical guideline, January 2018

https://www.nice.org.uk/guidance/ng82/resources/agerelated-macular-degeneration-large-print-version-pdf-4723369165

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