



Living with AMD

Tips & Tricks for
Age-Related Macular Degeneration



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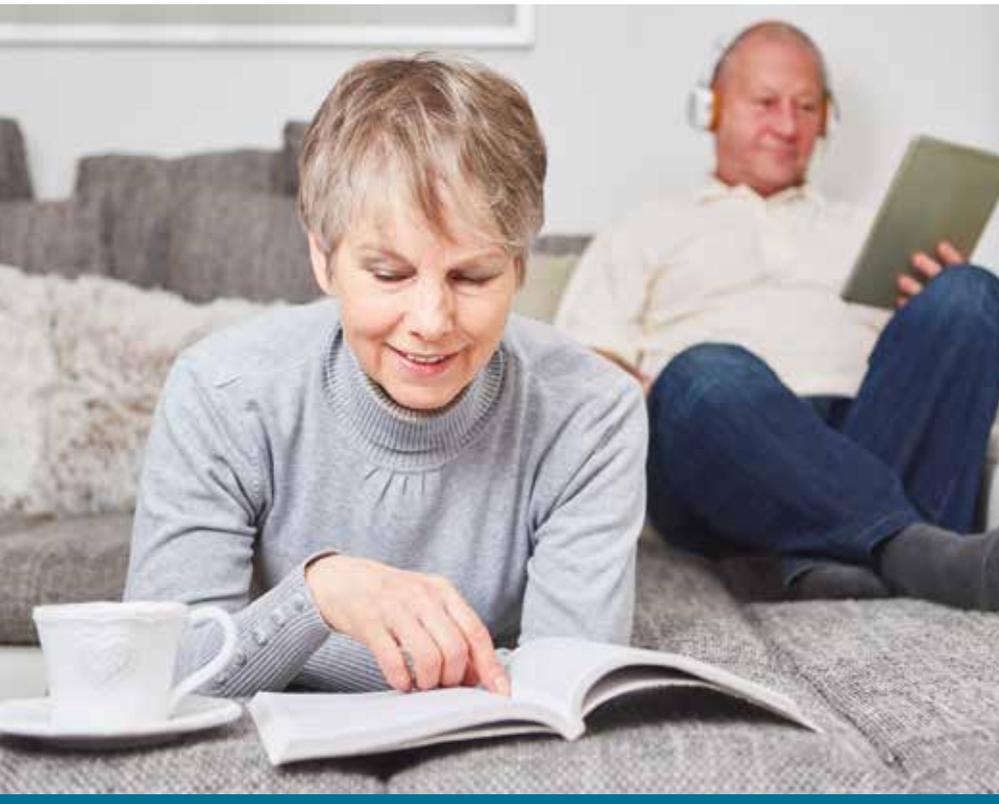
A guide for patients
and relatives

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Imprint

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Introduction

Dear Reader,

An eye disease such as **age-related macular degeneration (AMD)** is accompanied by a gradual deterioration of vision. Many patients associate this with restrictions in daily life and a loss of independence.

However, many aids and tips can help you manage your daily life with AMD and continue to lead a self-determined life.

This brochure provides you and your relatives with practical advice on how to make your life easier and safer.

We hope you enjoy reading this literature!



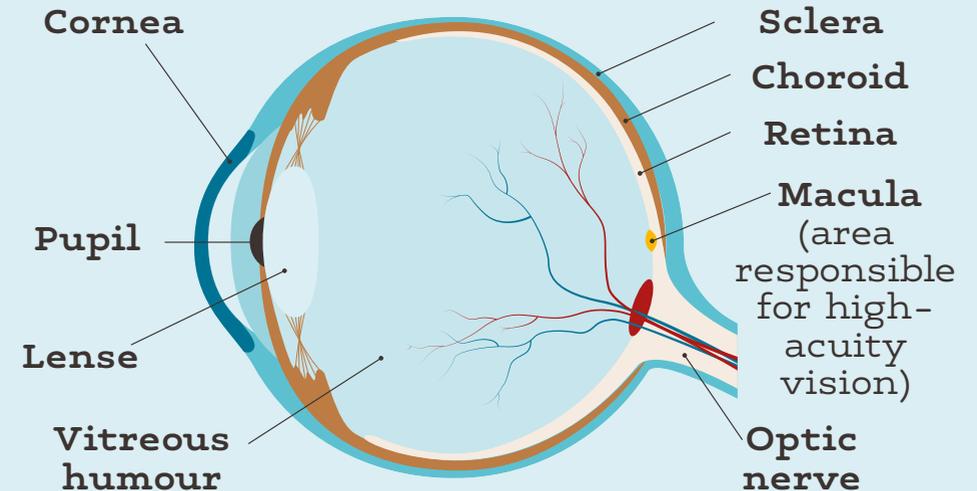
AMD

(age-related macular degeneration)



Retinal diseases can severely impair vision and damage eyesight. Among these is **age-related macular degeneration (AMD)**. With this chronically progressing eye disease, which usually does not appear until the age of 50, retinal damage occurs in the area responsible for high-acuity vision: the macula. This can cause **age-related blindness**.

Age-related macular degeneration is a slow progressing chronic disease and is not painful. If only one eye is affected, the healthy eye compensates for the loss of vision for a while, which means that those affected often do not notice their condition until much later.





One disease - two types

Dry **AMD** typically progresses quite slowly. Initially, drusen (deposits) form under the retina, and the patients notice only a slight loss of vision. In the later stage, retinal cells die off.

If the macula is affected by the damage, central vision deteriorates significantly.

In some patients with dry AMD, the disease pattern develops into a much more aggressive and faster progressing type: **wet AMD**.

In response to the drusen, new sick and less stable blood vessels form under the retina and grow into it. Fluid and blood leak out of the vessel walls, and the centre of the retina swells and/or scars. This process ultimately destroys the sensitive sensory cells of the macula

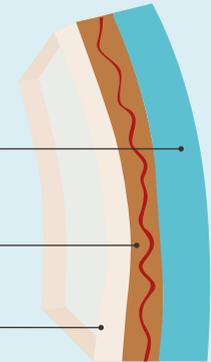
As it is a chronic disease, AMD progresses slowly when left untreated.

Healthy state

Sclera

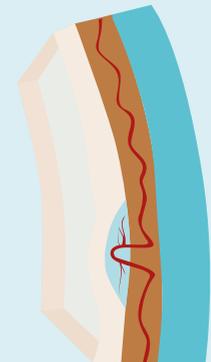
Choroid

Retina



State with wet AMD

Abnormal growth of leaking blood vessels leads to **fluid accumulation** in the retina





Important information about AMD therapy

Regular visits to the doctor are important

Most importantly, the fact that the patient is no longer able to read properly due to AMD and thus loses their independence, mobility and the ability to find their way around is a major challenge.

However, you as a patient or your relatives can make a significant contribution to maintaining or improving existing vision and thus to maintaining a self-determined life. What you need to do is very simple: Schedule necessary appointments for examinations and remain true to the treatment prescribed to you. Because treatment methods, such as injections with VEGF inhibitors, can only counteract deteriorating eyesight if administered regularly and permanently, and thus relieve both patients and relatives. Discontinuing therapy, however, would lead to further progression of the disease.



Tips for patients and relatives

- › Note regular examination and treatment appointments in your calendar and remind each other of them.
- › Even though a visit to the doctor may involve some effort and may be unpleasant: Only regular check-ups and ongoing treatment can prevent further deterioration of vision or even improve it again in some cases.
- › You can even go to medical appointments together. Important: Ask your doctor if something is unclear to you!
- › It can be helpful to talk to other people about the disease and experiences with treatment (see Service and Assistance, page 28)



Aids for day-to-day life

Managing day-to-day life with AMD

There are numerous daily aids and tips when at home or on the go to make your daily life easier and help you move more safely.

In this way, you can continue to live self-determined and safer lives in the future despite limited vision.



Daily aids at a glance

Classic and modern vision aids

Vision aids are the be-all and end-all for those suffering from limited visual acuity. There are a wide range of options. These include classic and modern seeing aids, the most important of which we would like to briefly introduce to you:

Magnifying vision aids

In order to be able to read small printed texts even with impaired vision, magnifying vision aids such as (electronic) magnifying glasses, (magnifying) spectacles or screen readers prove to be quite useful. These are available from opticians. As a rule, health insurance cover part of the costs after submitting a prescription.

Smartphones and tablets

These devices have a built-in read-aloud function. This allows you to have Internet pages including the online edition of newspapers, magazines and books read out loud to you. The same applies to emails and short messages. There are also numerous useful apps that increase brightness or perform the function of an electronic magnifying glass or reading device, among other things.

Readers

These devices replace independent reading by reading printed text into a computer with a camera and playing it back via voice output. Health insurance will cover the costs of such a device if necessary and if prescribed by a doctor.

Further aids and devices

Speaking aids

These include talking telephones, clocks, kitchen scales and thermometers, which are also equipped with practical buttons and large displays.

Label readers

Language information can be stored on special electronic labels, which can later be called up with a handheld device. The labels can be used several times, are washable and therefore also suitable for clothing.

Colour scanner

This device can be used to say the colours of different surfaces.

Health insurance company will cover the costs if a prescription from the ophthalmologist is submitted.

Marking and labelling

Objects that are difficult to distinguish from one another may be marked or labelled to make them easier to recognise. The marking should be easily palpable or coloured or contrasting, e.g. coloured adhesive tape or adhesive dots, touch points, differently shaped buttons, rubber bands, etc.



Practical tricks for daily life

- › Mark containers with coloured adhesive tape, labels or rubber bands in order to be able to distinguish them
- › Attaching tactile self-adhesive touch points to switches of electrical appliances
- › Identify matching garments with uniform buttons



Good entertainment is key

› Audio books

Don't want to miss out on the morning newspaper or bedtime reading in the evening? Then have your favourite literature read to you! Audio **libraries** offer a large selection of current light fiction, non-fiction and scientific works. Lending is free of charge for all those whose eyesight no longer permits independent reading. There is also the option of subscribing to current newspapers and magazines for a fee.

› Electronic books

Patients with low visual impairment can also read electronic books, known as e-books or e-readers. The benefit: Unlike the classic book, the font size and brightness can be adjusted as required.



Tips for patients and relatives

- › Get an overview together of the selection of useful aids and their functions. Some of these are available in medical supply stores, for example. You can also find a lot of information on the Internet.
- › Familiarise yourself with the function of the aids purchased or have them explained to you if necessary.
- › You may need to help your loved ones label and mark items.





Living and moving more safely – makes daily life easier

In addition to the aids presented, there are many practical tips to help you find your way around inside and outside your home and move around more safely.

Even small changes in the home can make your everyday life easier.

This includes providing sufficient lighting and avoiding tripping hazards. To help you find your way around, light switches as well as steps and furniture can be conspicuously marked. For cupboards and shelves: Always put all items back in the same place so that they are easier to find.



Practical tricks for daily life

- › Ensure that the lighting is sufficiently bright. When doing so, the appropriate intensity of light and right colour should be selected individually.
- › Install cupboard and night lighting and use motion detectors.
- › Secure loose mats and carpets with adhesive tape or use anti-slip underlays. Better yet: remove all loose floor rugs and runners.
- › Mark uneven floor areas with coloured adhesive tape.
- › Mark light switches and edges of stairs and furniture with coloured adhesive tape.
- › Have handrails fitted on both sides of the stairs.
- › Use cut-resistant gloves and a coloured cutting board in the kitchen.
- › Use place mats or tablecloths that stand out from the tableware.

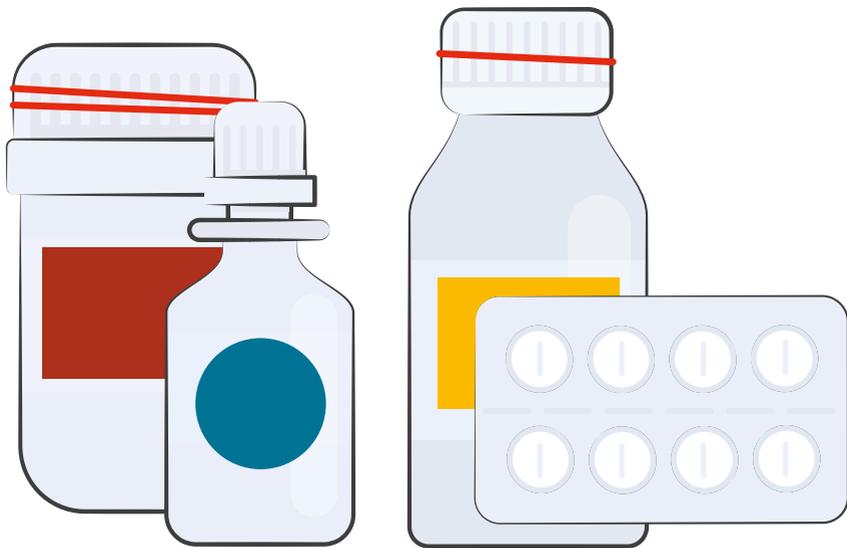


Better overview when taking medication

It often comes with age:

various medicines must be taken daily. It is easy to lose sight of things especially when your eyesight is limited.

Clear labelling can help you to continue taking your medication as prescribed.



Practical tricks for daily life

- › Together, attach an adhesive label in large letters on the package with the name of the medication and the prescription.
- › You can also use medicine dispensers with capital letters and time division, which can be found in specialist shops.
- › A simple reminder are rubber bands that you can attach to the package. For example, affix two rubber bands if you need to take a medicine twice a day.
- › Sort the available medicines together and pay attention to the expiry date.
- › Keep unused medicines in a place other than where you use them frequently.



Staying safe when on the go

When underway it is particularly important to avoid tripping hazards and dangers in road traffic.



Practical tips for outings

- › Take time for your journey or let relatives, friends or acquaintances accompany you.
- › To see better in sunlight, you can wear special glasses with yellow lenses and side glare protection.
- › Headgear with a wide brim or a cap can also shield blinding light.
- › Wear well-fitting shoes with flat heels and non-slip soles for a secure footing.

In case of emergency

In the event that you fall, injure yourself or need help for other reasons, you should take precautionary measures so that you can be helped quickly in an emergency.

Emergency numbers

Create a directory with phone numbers that you can call in an emergency. These can be phone numbers of relatives, friends or even organisations.

Keep the directory in a fixed, easily accessible place, such as next to the telephone.

You can also save the most important numbers on the speed dial keys of your telephone.

Call for help

If you have a mobile phone, it is best to carry it with you at all times. This way you can request help at any time and from any place.

Many charities offer a home emergency call. You can make an emergency call and call for help day and night with a small device that you wear on your body.

Leave a spare key to your apartment with neighbours or relatives who live nearby so that they have access to your home in an emergency.



Tips for patients and relatives

- › Ensure a better organisation in your home by discussing possible measures and implementing them together.
- › Move objects that endanger safety together out of the way.
- › Paths outside the home become easier and safer when accompanied by someone.
- › It is easier to take the correct medication with support, e.g. when filling the medication dispenser.
- › Create a telephone directory together with the most important telephone numbers in capital letters and keep it in a clearly visible place.





Service and assistance

Self-help groups

Exchanging information with other patients can help you to cope better with the stresses and strains of the disease. Relatives of AMD patients also find advice and help here.

- › **Deutscher Blinden- und Sehbehindertenverband e.V. (DBSV)**
Rungestraße 19, 10179 Berlin, Germany
Telephone: +49 (0)30 285 387-0
Email: info@dbsv.de
Internet: www.dbsv.org

- › **Blickpunkt Auge – Rat und Hilfe bei Sehverlust**
Counselling centres at
<https://blickpunkt-auge.de/kontakt.html>
- › **PRO RETINA Deutschland e.V.**
Kaiserstraße 1c, 53113 Bonn, Germany
Telephone: +49 (0)228 227 217-0
Email: info@pro-retina.de
Internet: www.pro-retina.de



**Find out
more here:
[www.mein-auge\(n\)licht.de](http://www.mein-auge(n)licht.de)**

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+49 (0)800 550 450 1**

