

**The Macular Disease Society**



**A guide to**

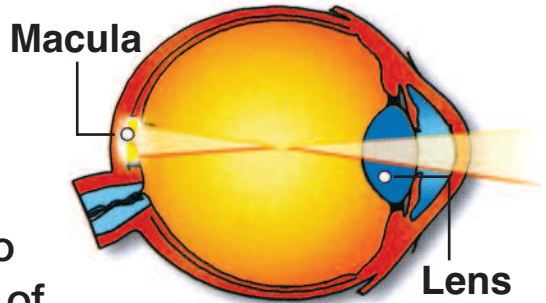
# **Macular Degeneration**



## Taking a closer look at

# Macular Degeneration

Macular Degeneration (MD) or macular disease are terms for conditions which lead to loss of central vision due to damage to the macula, a small part of the retina at the back of the eye.



It is the most common cause of visual impairment in the developed world. In the UK around 250,000 people are registered as visually impaired because of MD and roughly the same number are affected by it to a lesser degree.

MD includes juvenile macular dystrophies which are usually genetic and can develop from childhood to middle age. If MD occurs later in life it is often called Age-related Macular Degeneration.

The exact cause of MD is not yet known and there is currently no cure. But there are treatments for some forms of the condition and these are explained later in the booklet. As the UK population ages, MD will become increasingly prevalent so research into the cause, prevention and cure of MD is vital.



This booklet will explain what MD is, how it is diagnosed, what can be done and where to go for further information.



## What is MD?

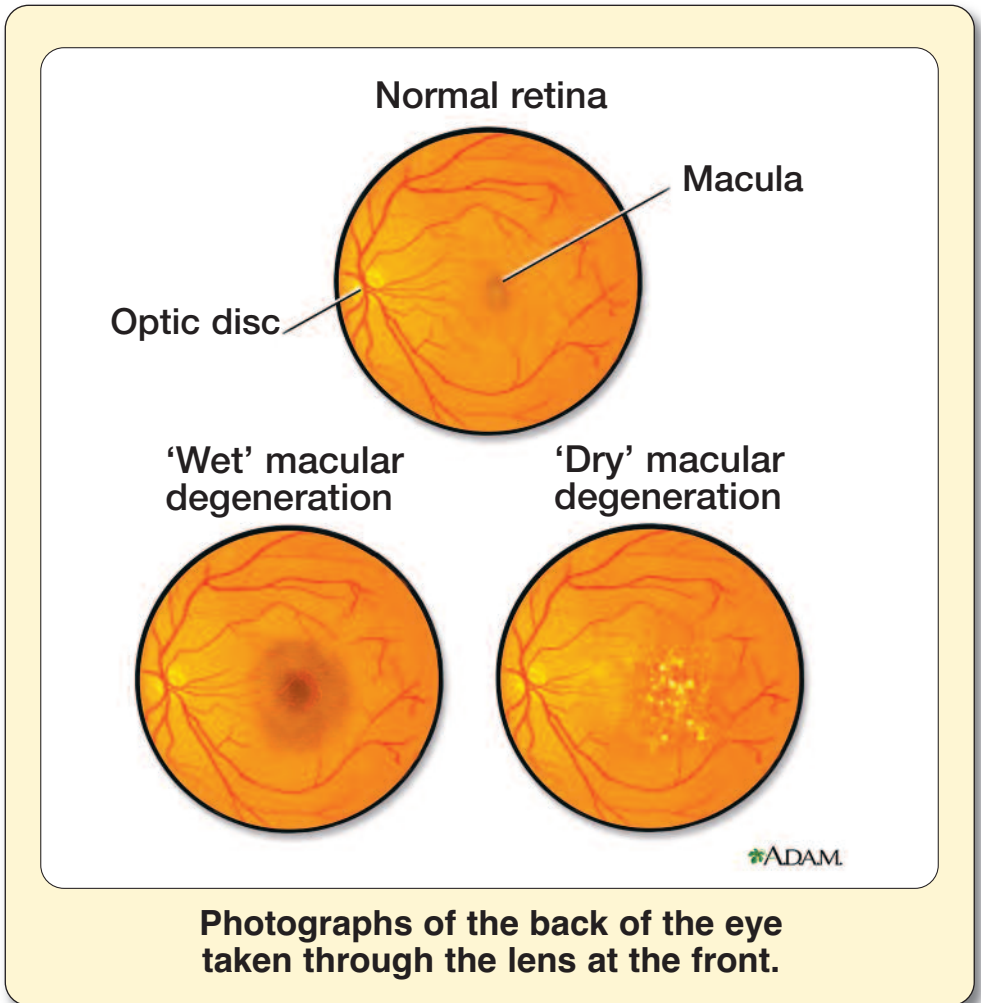
Cells in the macula break down, causing loss of sight in the central part of the field of vision. The side vision, known as peripheral vision, is unaffected.

Although the breakdown of macular cells may not begin until later in life, awareness and preventive measures should begin much earlier.

There are two types of MD – ‘Wet’ and ‘Dry’.

‘Wet’ MD occurs when tiny abnormal blood vessels begin to grow behind the retina toward the macula. They usually leak blood or fluid, damaging the macula and causing a rapid loss of central vision. Fast referral for treatment is essential for active Wet MD.

‘Dry’ MD causes a gradual deterioration of the macula, usually over many years. The name ‘Dry’ MD does not mean the person has dry eyes; the term is used to indicate that the deterioration has not been caused by leaky blood vessels as with ‘Wet’ MD.



**Photographs of the back of the eye taken through the lens at the front.**

A person may have the 'Dry' type in one eye and then develop 'Wet' in the same or the other eye. If MD occurs in one eye it is possible that it may affect the other eye within five years. The speed of progression of MD varies for every person.

## How does MD affect your vision?

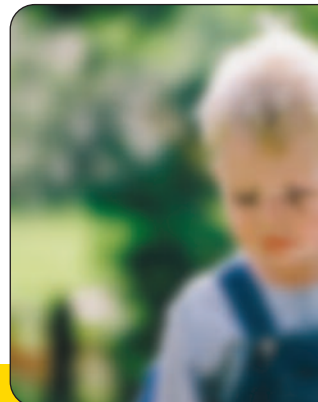
MD affects different people in different ways and you may not notice any change in your vision during the early stages of the disease. As the cells in the macula deteriorate, your ability to see will change.

Objects directly in front of you may change shape, size or colour and may seem to move or disappear. Your vision may become blurry, lines may become distorted or dark spots may appear in the centre of your field of vision.

MD may cause an area of blindness which, at normal reading distance, may block out several



Normal vision



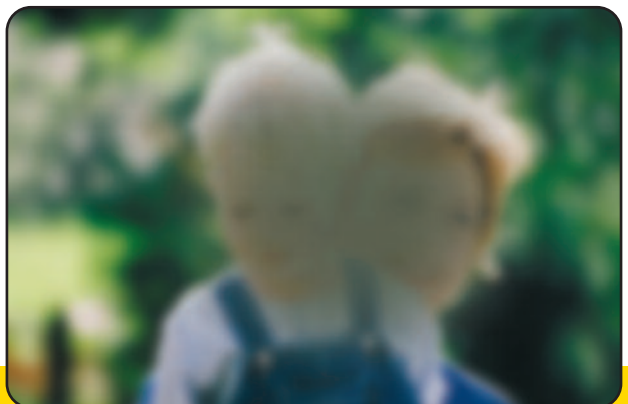
Vision with MD

words. You may also develop problems seeing in bright sunlight, experience glare, and find it harder to adapt from dark to light conditions.

Vivid hallucinations known as Charles Bonnet Syndrome are sometimes experienced (see page 26 for further information).

MD is a very frustrating condition which can greatly affect your day-to-day life by making it difficult to read, write, drive and recognise faces.

However there are techniques and equipment to help you make the most of your vision. Some practical tips can be found later in this booklet and there are more ideas in the Macular Disease Society's range of information leaflets.



Late stage MD

## What are the risk factors for MD?

The causes of MD are not fully understood but scientists believe that a combination of factors is involved:

- **Age**

Age is the main risk factor for developing MD. As we get older cell regeneration decreases, increasing the risk of developing macular degeneration.



- **Diet and Nutrition**

Though oxygen is essential for the human body it can also produce unstable molecules including “free radicals” which can damage cells or prevent cell repair taking place. Antioxidants are naturally-occurring nutrients, mainly in fruit and vegetables, which help the body fight the effects of free radicals. People with low levels of antioxidants in their diet

may be at increased risk of developing MD. Excessive alcohol may deplete the body's level of antioxidants. A diet high in hydrogenated or saturated fats increases the risk of developing MD. The body needs some fat to function and advice on “good fats” can be found on page 11. Individuals who are clinically obese may also be at higher risk of developing MD.

- **Smoking**

Smoking reduces the protective effects of antioxidants in the eye and damages the structure of the eye.



Smokers are three times more likely to develop MD than non-smokers. Ex-smokers were found to have only a slightly increased risk of developing MD than people who have never smoked.

- **Sunlight**

The cells of the macula are highly sensitive to blue light which occurs naturally in sunlight. Cell damage from blue light can lead to

## Risk factors continued

deterioration of the macula. People with light coloured eyes may be more prone to damage from sunlight. Filters which block blue and UV light help protect the eye and can reduce glare.

- **Genetics**

Many people develop age related MD partly because of faulty genes they have inherited from one or both parents. Therefore people with a family history of MD can have an increased chance of developing the condition themselves. When MD occurs in a younger person there is usually a genetic link.

- **Gender**

Being a woman over 75 doubles your chances of developing MD compared to a man of the same age.



## What can I do to protect my eyes?

While you cannot change your age, sex or family tree, there are lifestyle changes you can adopt that may protect your eyes:

- Stop smoking.
- Eat lots of fruit and green leafy vegetables.
- Ensure your diet is low in saturated fats and rich in Omega 3 fatty acids (oily fish).
- Wear lenses which block UV and blue light especially when in bright sunlight. Blue-blocking filters also reduce glare.
- Wear a hat with a brim or a visor that shades your eyes from direct sunlight.
- Keep your blood pressure down. People with hypertension are 1.5 times more likely to develop MD than people with normal blood pressure.
- Limit your alcohol intake to the recommended units per day.
- Visit your optician at least every two years for an eye test.



## Can nutrition help protect against MD?

Research suggests that nutrition plays an important role in MD. Changing your diet may help maintain eye health.



Epidemiological studies found that people who ate a diet rich in carotenoids (powerful antioxidants) had a lower risk of MD.

Lutein (loo-teen) and zeaxanthin (zeeah-zan-thin) were the carotenoids most closely associated with this reduced risk and are the main ones found in the macula. Meso-zeaxanthin is another carotenoid found in high concentrations in the centre of the macula. By contrast, beta-carotene is virtually absent from the eye.



## Carotenoid-Rich Vegetables

<b>Vegetable</b> (100 grams)	<b>Lutein / Zeaxanthin</b> (micrograms)
Kale	21,900
Spring greens	16,300
Raw spinach	10,200
Broccoli	1,900
Leaf lettuce	1,800
Green peas	1,700
Brussels sprouts	1,300
Sweetcorn	780
Green beans	740
Raw carrot	260
Tomatoes	100



Lutein and zeaxanthin can be found in almost all fruits and vegetables (see page 13) but particularly in dark green leafy ones such as spinach and kale. Increasing your intake of antioxidants could slow the progression of MD.

While there appears to be a link between carotenoid intake and MD, more research is needed. In the meantime, a diet including at least 2-4 servings a week of dark green leafy vegetables high in lutein and zeaxanthin may help to lower your risk of developing MD.



The recommended daily intake of all fruits and vegetables is five servings a day. A diet high in carotenoids may also protect against cataracts, heart disease and cancer.

## Vitamin supplements for healthy eyes

As a result of numerous research projects into vitamins, minerals and carotenoids, there are now many different vitamin supplements for eye health, some of which are pictured here.

If you are concerned that you are not able to obtain sufficient nutrients from your diet, you might consider taking a balanced antioxidant supplement. You should seek professional advice about possible side effects from your GP or pharmacist particularly if you take a combination of supplements and/or medication.



If you do buy supplements always buy from a reputable maker. Do not buy products which claim to “cure” or “reverse the effects” of MD. None currently exists.

## How is MD diagnosed?



The optometrist at your optician's practice is qualified to test sight, prescribe spectacles and to carry out examinations for eye disease. Some optometrists provide additional screening tests for early signs of MD including OCT (Optical Coherence Tomography), which generates cross-

sectional images of the retina, and other tests which measure macular pigment.

If your optometrist detects an eye health problem you may be referred to your GP, but preferably direct to a retinal ophthalmologist at the eye clinic, who is medically qualified in the diagnosis and treatment of eye disease.

The optometrist or ophthalmologist may:

- Use an eye chart to assess your vision.

- Put eye drops into your eyes to dilate (widen) the pupils so the back of the eye can be seen clearly. The drops may cause your vision to be blurred and your eyes may become sensitive to light so you should consider taking someone with you to your appointment.
- Ask you to look at an Amsler grid. You will be asked to cover one eye, fix your gaze on a central spot in the grid and say whether any of the lines are distorted or missing – this may help with precise diagnosis.

An ophthalmologist may also use fluorescein angiography for some patients. The pupils are dilated and a small amount of yellow dye is injected into a vein



in the arm. The network of capillaries at the back of the eye is photographed to pinpoint the source of trouble and start regular monitoring.

## Treatment and follow-up

Rapid diagnosis is critical. If you notice a sudden change in your vision go without delay to your optometrist (optician) who should refer you direct to a retinal specialist.

For suspected Wet MD, a patient should be seen urgently at a retinal clinic within a week if possible. More than 3 weeks is too long a delay for this appointment. For Dry MD change will be more gradual and a patient should receive an ophthalmic assessment within 3 months.

Patients recently diagnosed with Wet MD may be suitable for treatment with drugs injected into the eye. These inhibit the growth of new blood vessels and can stabilise a person's vision.



Some people may be offered an older treatment called Photodynamic Therapy in which a cold laser is used to seal the leaking blood vessels. Sometimes both treatments are used together.

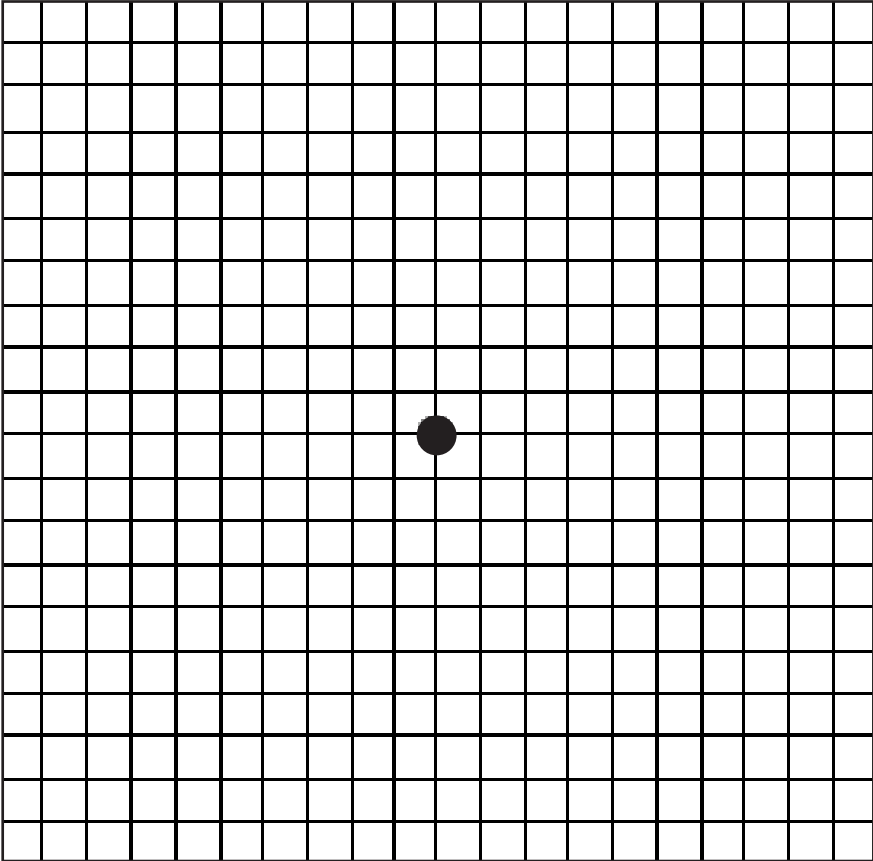
Research continues into new drugs and therapies and cell transplant techniques.

All patients, whether they have Wet and/or Dry MD, should be given the following help:

- Referral to a low vision clinic for equipment and advice to help cope with loss of central vision.
- Referral to a social services sensory impairment team if necessary for practical advice and assistance such as daily living skills and mobility.
- Discussion of diet and lifestyle.
- Signposting to support organisations: The Macular Disease Society and the local society for visually impaired people.
- Signposting to the employment service for help at work and to the 'Access to Work' scheme.

# Amsler Grid

Monitor your vision at home.



## **Amsler Grid directions for use**

- 1. Hold the grid at your normal reading distance – use spectacles if needed (but not bifocals or varifocals).**
- 2. Cover your left eye and look at the dot in the centre.**
- 3. Check if all the lines appear straight and even, or if any are wavy and distorted.**
- 4. Check to see if any pieces of the grid are missing.**
- 5. Next cover your right eye and repeat.**
- 6. Perform this check as often as your optometrist or ophthalmologist recommends.**
- 7. You can use the Amsler grid at home to monitor changes in your vision. If the lines appear wavy and distorted, if there is a sudden change in your vision, or if there are any other new abnormalities contact your ophthalmologist immediately.**

## Practical tips for making the most of your vision

- Improve the general lighting in your home and work place. You can increase lighting levels and still control glare. Modern low energy bulbs are cheap to run. A low vision specialist can give advice.
- Use adjustable, cool-to-the-touch task lighting for near tasks. Daylight bulbs can be helpful.
- Spectacles with filters which block blue light and UV light help protect the eye and reduce glare.
- Use bright and contrasting colours to help differentiate between objects.



There is a wide range of equipment available to help too:

- Magnifying devices are helpful. Use different magnifiers to suit specific tasks.

Magnifiers are often loaned free of charge through a local low vision service.



- Computers combined with scanners and audio conversion can be helpful.
- Large print books are available from libraries.
- Audio versions of books, newspapers and magazines are also available.
- You may want to use talking equipment such as watches, microwaves and kitchen scales.
- Tactile bumps can be used to indicate frequently used settings on cookers and washing machines.
- large face clocks/ watches, large print stickers for keyboards, telephones with large numbers and brightly coloured kitchen implements can be helpful.



## Other things you can do to help yourself

To find your way to the best advice and equipment for you, ask for a low vision assessment from your local social services department.

You may wish to speak to your consultant about registering as sight impaired or severely sight impaired.

This will entitle you to claim services for visually impaired people.



Keep a record of the key information and advice you are given during clinical and social care appointments, by making notes or by using a dicta-phone or other recorder.

## **Eccentric Viewing**

People with central vision loss can still see with their peripheral or side vision. Eccentric Viewing is a technique which helps a person to make best use of their side vision. Though it does not work for everyone, many people find it very helpful. The Macular Disease Society and some other organisations offer training in Eccentric Viewing. You can find out more from the Society.

“I’m so pleased with the results – I’m now able to get large print books from the library again and read them so much quicker than I used to before I had the training.” Molly Owen



## **Charles Bonnet Syndrome**

Charles Bonnet Syndrome (CBS) is a side-effect of vision loss in some people which causes them to have visual “hallucinations”. These can be very vivid and sometimes alarming.

Images can range from simple geometric patterns or grids to complex pictures of people, animals or landscapes. The hallucinations are caused by the brain’s normal response to sight loss.

As the cells in the retina are damaged they send fewer messages to the brain and the brain cells which process what we see receive less stimulation. In some people these cells can begin to fire spontaneously creating images of things which are not really there.

People with MD who do not know about CBS sometimes fear they are developing conditions such as dementia so it is very important to remember that CBS is quite different and not a sign of mental illness. CBS hallucinations seem to occur most often when a person is relaxed and quiet and can sometimes be dispelled by

getting up and moving around or changing the ambient lighting conditions.

Not everyone with vision loss experiences CBS and for most people it passes with time. You can find out more from our Helpline and if your CBS is troubling you, perhaps you might wish to speak to our Counselling service.



“It is vital to publicise this silent terror. Of the calls received on our Helpline, many are referred on for counselling because of extreme distress. Callers genuinely believe they are going mad. When this phenomenon is properly explained a great sense of relief is experienced.”

**Dennis Lewis, Head of Counselling, MDS**

# The Macular Disease Society

The Macular Disease Society is a national charity dedicated to helping people with MD and to sponsoring research. Our total membership is over 16,000 and includes members in 28 countries outside the UK.

Our main activities are to:

## Provide information and support:

- helpline
- counselling service
- low vision and rehabilitation support
- range of publications, conferences and website
- 200 local support groups across the UK



**MDS Groups**



**Helpline**



**Information**

## **Sponsor research into:**

- a cure
- new treatments
- techniques to improve quality of life and increase independence



**Research**

## **Campaign to:**

- raise awareness of MD and its effects
- obtain funding for treatments
- improve access to treatments and low vision services

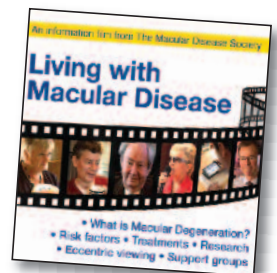


**Campaigning**

## **Please join the Macular Disease Society**

For just a small annual subscription you will receive all the membership benefits and help others with the condition too.

As a member you will receive an introductory DVD explaining macular disease, its effects and treatments.

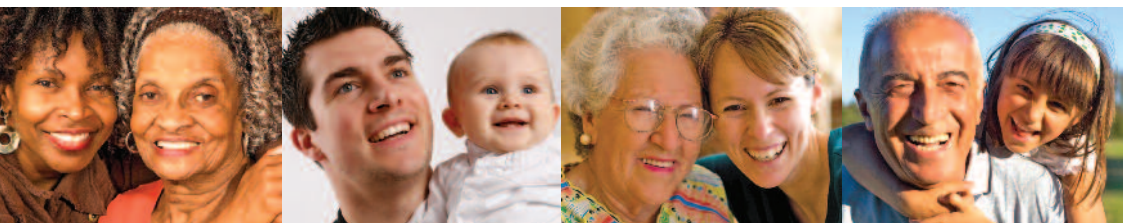


You will also receive our quarterly magazine and our annual scientific review, in large print or audio format, and will be given the opportunity to join a local support group or talk to someone who has MD on the phone.



People who have MD frequently receive less help than they need. You will be part of a society dedicated to helping. Your support gives us a stronger voice to campaign with and without your fees and gifts we can't sponsor vital research or provide much needed services, so please join us.

**We welcome all who have an interest in MD** including people who have MD, relatives, carers, and friends, healthcare professionals and others working with people who have impaired vision.



Joining is easy – fill in the form opposite and return it to us, phone 01264 350551 or go to [www.maculardisease.org](http://www.maculardisease.org) to join using your credit or debit card.

**Ordinary Membership:** £15 per annum

**Overseas Membership:**

£25 per annum – Europe / £30 per annum – Rest of the World

To join now return this form with your cheque or join by credit card online at: [www.maculardisease.org](http://www.maculardisease.org).

## **I wish to join the Macular Disease Society**

Name (Mr, Mrs, Miss, Title) \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

Postcode \_\_\_\_\_ Tel. \_\_\_\_\_

Email \_\_\_\_\_

Date of Birth \_\_\_\_\_

I enclose my cheque for £ \_\_\_\_\_ for annual membership

I enclose a donation of £ \_\_\_\_\_

(UK cheques only please made payable to the 'Macular Disease Society')

**Gift Aid** - If you are a UK tax payer we can claim back income tax from the Inland Revenue. For every £1 of your membership fee or any donation you make we can claim at least an extra 25p at no additional cost to you. To enable us to do this please tick the box below and sign the declaration:

I am a UK tax payer and would like the Macular Disease Society to treat all donations I make from the date of this declaration until I notify you otherwise as Gift Aid Donations

Signature \_\_\_\_\_

**Return this form to the Society's address on the back page.**



# **The Macular Disease Society**

**Web: [www.macular-disease.org](http://www.macular-disease.org)**

**Email: [info@macular-disease.org](mailto:info@macular-disease.org)**

**Membership Secretary: 01264 350 551**

**Helpline: 0845 241 2041**

**PO Box 1870, Andover, Hampshire, SP10 9AD**

**Registered Charity No.1001198**

**The Macular Disease Society relies heavily on donations and legacies to continue to help people with MD. -**

**If you have found this booklet useful you might like to make a donation. Simply add an amount to your membership fee, visit our website to make an online donation, or send a cheque made out to the Macular Disease Society. -**

## **To obtain further copies of this booklet:**

**Hospitals, Opticians, GPs, Local societies for the blind etc please email or fax the quantity required, with your mailing address asking for booklet MDS002. Email: [mds@tmbmailing.co.uk](mailto:mds@tmbmailing.co.uk) Fax: 01732 886 345**

**Please note: bulk orders of booklets are not available from the Society's Helpline, (although individuals may ask for single copies)**

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