

# Supporting someone with a macular condition

Support throughout central vision loss

Advice for family and friends

Information and support for anyone affected by  
macular degeneration. Call 0300 3030 111.

This leaflet provides advice on how to support members of your family or friends who have a macular condition. It also advises on how to care for your own well-being, as supporting someone with a macular condition can be challenging.

## Background info

There are many forms of macular disease including genetic conditions which affect young people. When macular disease appears in later life, usually over the age of 60, it is called age-related macular degeneration (AMD). There are two forms

of AMD; **dry** and **wet**. In dry AMD, the macula gradually deteriorates as retinal or macula cells die and aren't renewed. There is currently no treatment for dry AMD, it's progression can develop over months or years. Life can carry on as normal for some time.

In wet AMD, abnormal blood vessels grow into the macula. They are fragile and leak and scar the macula. This leads to rapid loss of central vision. It can develop suddenly, however it can be treated if caught quickly. If someone has wet AMD

fast referral to a retinal specialist is essential.

### Tips for people newly diagnosed:

- talk to other people with AMD, such as through our local support groups
- improve lighting at home. Make everything big, bright and bold
- get as much information as possible on the particular condition to help prepare for the future

### Mythbuster!

When diagnosed people often hear that they will 'go blind'. Someone with a macular condition

will not go completely blind. AMD affects central vision but not, normally the peripheral vision.

### Providing support

A macular condition can bring practical, financial and emotional life changes for those diagnosed and for their family and friends.

Depending on the amount of sight loss that someone has experienced, they may need to help with:

- paperwork, shopping, or cooking at home
- choosing suitable low vision aids

- contacting welfare or social services
- adapting lighting in the home

People with a macular condition can become reliant on others to complete some everyday tasks for them. Everyone is different, so everyone's level of independence is different.

It is important to respect individual abilities and allow someone to carry on with everyday tasks, even if they don't do them to your standard.

It can be very difficult for you, as someone

providing support, to 'let go'. However, it's important that the person with the macular condition remains as independent as possible.

### **Mythbuster!**

People with sight loss do not have to be registered as sight impaired in order to get a social services assessment.

Whatever the degree of sight lost, if the sight loss is affecting their daily life ask for an assessment. This could include the risk of burns, falls or trips.

## Understanding sight loss

Talk to the person affected. Try to understand how their sight has changed and how they want to be supported. Before you do anything on their behalf, ensure that you have their permission to act.

Two useful questions to ask someone with a macular condition:

### **1. What can you see and not see?**

Understanding the person's sight loss can help when making simple changes to home lighting, room layouts or buying low vision equipment. Remember, any change

has to suit the person with the condition, not what you feel is right.

## Top tips

It can be difficult to understand central vision loss. It may appear that a person can see some things when they want to. This is because parts of the macula may still be working. View our simulation photos [www.macularsociety.org/about-macular-conditions/simulation-pictures](http://www.macularsociety.org/about-macular-conditions/simulation-pictures)

**2. It's common for people losing their sight to see things that aren't there. Is this happening to you?**

As the eye adapts to sight loss it's common to experience visual hallucinations known as Charles Bonnet Syndrome. Some people enjoy their hallucinations – others find them distressing. Our helpline offers support to cope with hallucinations. Call 0300 3030 111.

### **Emotional support**

The experience of being diagnosed with a macular condition can be like the grieving process of bereavement. People will experience feelings of denial, anger, depression and acceptance. Personalities can change.

Someone with a macular condition won't look any different than before they developed the condition. However, they may not be able to recognise friends and family. This can be distressing. Some people with macular conditions worry that they appear rude because they walk past people they know without realising it.

People with a macular condition often have to give up driving because of their sight loss. This can be upsetting. Yet it need not be the end of a social life. They can still keep in touch with old friends and even make

new ones, such as through our support groups.

**The cost of running a car could be used towards taxi fares or community transport.**

It's helpful to focus on the positive and what people can do rather than what they can't.

### **Financial support**

Make sure that any benefits or other entitlements are being claimed. Attending hospital appointments and equipment like lighting will be unexpected costs. Personal Independence Payments or Attendance Allowance may be

relevant. Citizens Advice should be able to advise.

### **Help yourself too!**

When someone is first diagnosed everyone rallies round. Supporting someone with a macular condition is a long-term commitment.

Anyone providing support needs to consider what help they can offer and what else is needed. Don't be afraid to ask for help – from family, friends and health and social services – and we're here for you too!

Providing support for someone else can be demanding. You may

be doing this alongside other responsibilities, such as working and/or raising a family or providing support for others.

At times you may feel ill-equipped, frustrated, overwhelmed or afraid of the future. These feelings are normal. Good planning and support networks can make a huge difference.

You can only support others if you're in good health too. Eating a healthy diet, regular exercise, staying in touch with friends and keeping up with hobbies will help you cope with stress.

Holidays and short breaks are possible. For example freezing batch meals that can be microwaved and asking neighbours to pop in for a chat can allow you to have a well-earned break!

You don't need to cope alone. Your support circle could include other family, friends, your GP, others in a similar situation, the Macular Society, and of course the person with the condition.

If you are worried you might get the condition? Knowing the risk factors will mean you can protect your own sight.

## The future

Living with a macular condition is a journey for you and for the person with the condition.

Further sight loss, even years after first diagnosis, may still be upsetting. It may evoke the same feelings as when first diagnosed.

Remember, the Macular Society is here for you at every stage. Helpline **0300 3030 111**

## Some other leaflets

- Registering as sight impaired
- Visual hallucinations
- Daily living skills

Our leaflets are available in large print and audio and can be downloaded from

[www.macularsociety.org](http://www.macularsociety.org)

## Useful links

Macular Society

[www.macularsociety.org/family-and-friends](http://www.macularsociety.org/family-and-friends)

Talk to other family and friends. Join one of our forums.

[www.macularsociety.org/forum](http://www.macularsociety.org/forum)

Citizens Advice Bureau

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Carers Trust

[www.carers.org](http://www.carers.org)

Carers UK

[www.carersuk.org](http://www.carersuk.org)

## How we can help

We are the national charity for anyone affected by central vision loss. We provide free information and support to improve lives today. We fund research so that one day we can overcome macular disease.

You don't have to be a Society member to use our services. We provide:

**Helpline** – confidential advice and information on all aspects of macular disease, including diagnosis, treatment and living with central vision loss.

**0300 3030 111**  
**Monday to Friday**  
**9am – 5pm**  
**help@**  
**macularsociety.org**

**Counselling** – It's natural to feel upset or angry when you're told you have a macular condition. Many people find it helps to talk, in confidence, to a professional counsellor.

**Support Groups** – we have a network of almost 300 local groups

**Befriending** – Having a macular condition can leave you feeling isolated especially if it's hard to get out and about. Your

dedicated befriender will call regularly for a friendly, social chat about anything you like including, but not always, macular disease.

**Advocacy** – help accessing treatments

**Skills for seeing** – training to make best use of remaining sight

**Treatment buddy** – chat to people who've had treatment by injection for support and advice

**Charles Bonnet buddy** – chat to others who've experienced visual hallucinations as a result of a macular condition

## Join us

Many people join the Macular Society so that they can make a difference.

Your support now will give desperately needed help to people losing their sight.

To join today call

**01264 350 551**

**info@  
macularsociety.org**

and be part of a campaign for better care and fund research to find a cure.

AMD causes more than half of all blindness in Britain. 600,000 people have AMD and another 200 people are diagnosed every day.

We urgently need to find a cure and you can help today. We are the only UK charity dedicated to funding research into macular disease.

To make your vital donation and move us closer to a cure call us today or go online.



**Macular Society**

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

**Helpline 0300 3030 111**

**[www.macularsociety.org](http://www.macularsociety.org)**

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**@MacularSociety**



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Macular Society is the trading name of the Macular Disease Society.

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