

Supporting someone with a macular condition

Advice for family and friends.

This leaflet is available on audio CD.

**You don't have to face macular disease alone.
For the best information and support call us on
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 your own wellbeing, as supporting someone with a macular condition can be challenging.

What is macular disease?

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 55, 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 macular cells die and aren't renewed. There is currently no treatment for dry AMD. Its progression can develop over years and life can often 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, but it can be treated if caught quickly. If someone develops wet AMD, a rapid

referral to a retinal specialist is essential.

It is important to remember that someone with a macular condition will not go completely blind. AMD affects central vision but normally not peripheral vision.

Understanding sight loss

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.

Talk to the person affected. Try to

understand how their sight has changed and how they want to be supported. 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.

2. It's common for people losing their sight to see things that

aren't there. Is this happening to you?

As the brain 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.

For more information about Charles Bonnet syndrome, see our 'Visual hallucinations' leaflet at [macularsociety.org/resources](https://www.macularsociety.org/resources)

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 lost, they may need 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, and so is the level of help they will need or want.

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.

Top tip: Local councils provide a social services assessment for anyone whose daily life is being affected by their sight loss. They could offer rehabilitation training, low vision aids and

practical help to ensure people with sight loss can continue to live independently.

Emotional support

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

Someone with a macular condition won't look any different from 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.

People with a macular condition often have to give up driving because of their sight loss. This can be upsetting. This doesn't mean 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 (see page 11).

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

For more information about the emotional effects of macular disease, see our 'Emotional impact of sight loss' leaflet at macularsociety.org/resources

Financial support

Make sure that any benefits or other entitlements are being claimed. Attending hospital appointments and equipment like lighting will bring unexpected costs.

A person with macular disease may be eligible for Personal Independence Payment (PIP) if they are aged

between 16-64 or Attendance Allowance if they are aged over 65.

A carer could apply for Carer's Allowance if there are substantial caring needs. For more information go to

[gov.uk/pip](https://www.gov.uk/pip)

[gov.uk/attendance-allowance](https://www.gov.uk/attendance-allowance)

[gov.uk/carers-allowance](https://www.gov.uk/carers-allowance)

Being registered as sight impaired often makes it easier to get practical help and claim certain benefits.

For more information on the registration process, see our 'Registering as

sight impaired' leaflet at **[macularsociety.org/resources](https://www.macularsociety.org/resources)**

Help yourself too

Supporting someone with a macular condition is a long-term commitment. Anyone providing support needs to consider what help they can offer and what support they need.

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. 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.

Top tip: 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.

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.

The Macular Society is here for you at every stage. See page 10 for ways we can help.

Information is key

It can seem daunting to support someone with a macular condition, especially if they are still trying to understand it themselves. We worked with experts and people with personal experience of sight loss to produce an easy-to-understand website and a series of leaflets to help both of you adapt and live well.

And you don't have to go through it alone – thousands of people with a similar experience share their tips and stories on our Facebook page and online forum.

You can find our full range of patient information at macularsociety.org/resources

Join us online:



facebook.com/macularsociety



twitter.com/MacularSociety



youtube.com/macularsociety

HealthUnlocked

healthunlocked.com/macularsociety

Beating Macular Disease

Macular disease is the biggest cause of sight loss in the UK, with around 300 people diagnosed every day.

The Macular Society is the only charity determined to beat the fear and isolation of macular disease with world-class research, and the best advice and support.

To support people affected by macular disease now, the Macular Society provides a range of support, information and services:

The **Advice and Information Service (0300 3030 111)** is available Monday to Friday, 9am to 5pm. Alternatively, you can email help@macularsociety.org

Our **website** provides a wide range of information and resources for people affected by macular disease. You can also find out more about the services we offer. Visit it at macularsociety.org

Our network of over 400 **Macular Society Support Groups** stretches across the UK. Each one offers practical and emotional support for people with

macular disease, from those living with it today.

We provide a free, confidential **Counselling Service** over the phone. Call the Advice and Information Service for more information.

Our Telephone Befriending Service pairs you up for regular telephone calls with another person with macular disease who knows what it is like to live with the condition. Calls can be about anything, and provide friendly support.

Our Treatment Buddies Service will connect you

with someone else who has received treatment for macular disease to talk you through the process and any worries you may have.

Skills for Seeing training can help you with techniques to make the most of your vision.

Our Advocacy Service has been set up to help people with macular disease who are finding it difficult to access the treatment or care that they are entitled to. We also help friends, family and carers acting on behalf of people with macular disease.

Working with you to Beat Macular Disease:

- We provide the best advice and information on living with macular disease.
- Macular Society Support Groups can help you to beat the isolation of macular disease, by connecting you with other local people who know what you're going through – offering support and companionship.
- Our research programme is focused on finding new treatments and a cure to Beat Macular Disease forever.

Macular Society

PO Box 1870, Andover SP10 9AD

01264 350 551

macularsociety.org

info@macularsociety.org



@MacularSociety



/macularsociety

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Patient Information Forum

