

Supporting someone with a macular condition

Advice for family and friends

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

Introduction

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 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 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 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 feelings of denial, anger, depression and 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. 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 (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 www.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

www.gov.uk/pip

www.gov.uk/attendance-allowance

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 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 www.macularsociety.org/resources

Join us online:



facebook.com/macularsociety



twitter.com/MacularSociety



youtube.com/macularsociety

HealthUnlocked healthunlocked.com/macularsociety

How we help

The Macular Society helps people adapt to life with sight loss, regain their confidence and independence and take back control of their lives. We are one of the few sight loss charities that actively fund and support medical research into macular disease.

All our services are free to people with macular conditions, their family and friends.

Helpline

We offer 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

When a person is told they have a macular condition, it is natural for them to feel upset or angry. Many people find it helps to talk in confidence to a professional counsellor.

Support groups

We have a network of almost 380 local groups. A list of our groups can be found at www.macularsociety.org/groups

Befriending

Having a macular condition can leave a person feeling isolated, especially if they find it hard to get out and about. A dedicated

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

Advocacy

We offer help to those struggling to access treatments.

Skills for Seeing

Our training programme can help people make the best use of their remaining sight.

Treatment buddy

It can be beneficial to talk to people who've had treatment by injection, for support and advice.

Six months free membership

If you would like to receive regular updates about living with macular conditions, treatments and medical research to find a cure then membership is for you.

Join for free today by calling 01264 350 551 or go to www.macularsociety.org/6months

We rely on donations to fund support services and research to find a cure. To donate please go to www.macularsociety.org/donate or call 01264 350 551.



Macular Society

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