

Emotional impact of sight loss

The biggest cause of sight loss in this country is macular disease. Coping with your emotions after being diagnosed can be difficult.

**No one need face macular degeneration alone.
For information and support call 0300 3030 111.**

Introduction

More than 600,000 people in the UK have a macular condition. The most common is age-related macular degeneration (AMD).

Many areas of life are affected by macular disease, such as reading, writing, watching TV, driving, recognising faces and communicating visually. This reduced quality of life can have a huge impact on the way people think and feel about themselves and can be difficult to accept.



Common emotional reactions

Fear

It is very common for people to fear blindness. A study found that patients equate the impact of loss of vision with suffering a stroke or having an advanced form of cancer, so it's vital to get the support you need as soon as possible. Please refer to our Helpline information on page 7.

Grief

Many people with AMD describe the impact of losing their sight as like bereavement. They 'mourn' the loss of their sight and experience

many of the same stages of grief: denial, anger, bargaining, depression and eventually some acceptance. If you are experiencing any of the above, our Counselling service could help. See page 8 for more information.

Isolation

One of the first experiences many people have is a feeling of isolation. This can develop over weeks, months and sometimes even years. People feel anxious and withdrawn and this can cause them to step away from social situations.

If you feel isolated, please read our Befriending service information on page 9.

Depression

It is very common for people who have AMD to have low self-esteem and feel depressed. In fact, people with AMD are seven times more likely to feel distressed or depressed than people with no sight loss. Please refer to our Groups information on page 9.

Other emotions

Shock, anger, disbelief and denial are all common emotions. In extreme cases

people can even experience suicidal thoughts.

People tell us...

“I don’t want to be a burden to my family and friends”

Senior family members, who are more used to giving help and advice, can suddenly find themselves needing support. They sometimes struggle to come to terms with this.

“People will think I’m stupid”

Poor vision can affect even simple tasks. People can become more accident-prone and may worry about

how this is seen by others. People with sight loss are twice as likely to fall. Fear of falling might stop you doing the things you love or getting out of the house.



“I feel a fraud”

While macular disease can cause serious sight loss, it may not

be obvious to anyone else. This can lead to reluctance to appear in public places. Some people don't want to go out at all.

“I don't know how to tell my family”

Many people with macular disease say that one of the most difficult situations to deal with is telling others about their sight condition. They are scared about how their family and friends, neighbours, colleagues and other people will react.

It is extremely common for people to feel

apprehensive about 'going public' with their diagnosis. Call our Helpline for advice about how to explain your sight loss to other people.

Family and friends

The family and friends of a person with macular disease can also be affected by significant changes in emotions.

Supporting someone with a macular condition can be a long-term commitment. It can be frustrating and overwhelming. These feelings are normal and with the

right support, family and friends can learn to cope very well.



We provide a leaflet entitled 'Supporting someone with a macular condition' with plenty of advice for the people around you.



How the Macular Society can help

Many people appreciate being able to talk about their feelings in a safe and confidential way to someone outside their family or circle of friends.

The Macular Society has a range of free services to help you share your feelings and explore ways of coping with the changes to your life.

Helpline

Our Helpline should be your first point of call. Our specialist staff listen, offer support

and provide information and advice about all aspects of central vision loss. Calls are confidential and no question is a silly one.

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



The Helpline can also tell you about our other services:

Counselling

It is natural to feel upset or angry when you're told you have a macular condition. Many people find it helpful to talk in confidence to a professional counsellor.

Our free telephone counselling service is available to anyone affected by a macular condition at any time during their sight loss journey. It is also available to family, friends, carers or anyone supporting

someone with a macular condition.

To register, call our Helpline. They will pass your details on to the service co-ordinator and one of our team will normally call you within one week for an assessment.

Sessions are held over the phone enabling us to offer a UK-wide service. We will provide up to six sessions, usually on a weekly basis, although extra sessions can be provided if needed. Sessions can be arranged around eye appointments.

All of our counsellors are fully qualified and members of the British Association for Counselling and Psychotherapy (BACP).

Support groups

We have a network of almost 380 local groups providing friendship, practical advice and a

sympathetic ear to thousands of people with macular disease. To find your local group, visit www.macularsociety.org/groups or call the Helpline.

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 only, macular disease.

Advocacy

We offer help to those struggling to access treatments.

Skills for Seeing

Our training programme can help you make best use of remaining sight.

Treatment buddy

If you have been told you need injections and are worried, you can chat to people

who've had injections for support and advice. Call our Helpline for more information.

Getting practical help

Registering as either 'sight impaired' or 'severely sight impaired' (formerly 'partially sighted' and 'blind' respectively), often makes it easier to get practical help and claim benefits, which in turn may help you overcome some emotional barriers.

For more information please refer to our 'Registering as sight impaired' leaflet.

People we help

We have helped many people with macular disease cope with their emotions.

Visit www.macularsociety.org/people-we-help to read some of their stories.



Explaining AMD to your friends and family isn't easy, from a medical point of view or an emotional one. It is important to be understood so you can receive the best support.

To help with this, we have created a short video featuring a character called Mac.

You can watch this video at www.macularsociety.org/mac-macula

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.



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