

# What next? Your guide to Dry AMD and finding advice, information and support.

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This booklet is available in accessible formats such as large print, braille, electronic, and audio. Ask Wales Council of the Blind for copies on telephone **029 2047 3954** or email **support@wcb-ccd.org.uk**

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**Further information:** To find out more about any of these sources of help and support, contact **Wales Council of the Blind**, who will direct you to the right contacts or arrange for the organisations to contact you.

- Call: **029 2047 3954**
- Email: **support@wcb-ccd.org.uk**
- **<http://wcb-ccd.org.uk/support>**

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## Why have I been given this booklet?

You have been given this booklet to accompany your **Certificate of Vision Impairment**. The certificate is a useful document as it provides evidence of your eligibility for various kinds of support. It is also a necessary step to becoming **registered** with your local authority as either Sight Impaired (SI) or Severely Sight Impaired (SSI). Getting registered is another gateway to support.

# Understanding your diagnosis.

## There are two forms of AMD – dry and wet.

**Dry Advanced Macular Degeneration (AMD)** is a gradual deterioration of the macula as the retinal cells die off and are not renewed. The term dry does not mean the person has dry eyes, just that the condition is not wet AMD.

The progression of dry AMD varies but in most people it develops over many months or years. Often people carry on as normal for some time.

**Wet AMD** develops when abnormal blood vessels grow into the macula. These leak blood or fluid which leads to scarring of the macula and rapid loss of central vision over weeks or months. Wet AMD can develop very suddenly.

Around 10 to 15 per cent of people with dry AMD develop wet AMD, so if you have been diagnosed with dry form of the disease and notice a sudden change in your vision, contact your high street optometrist or optician urgently because **there is treatment available for Wet AMD, to prevent further sight loss.**

## Continue to visit your high street optometrist.

It's important that you continue to maintain your general eye health. This can be checked by your high street optometrist or optician. They can generally see you quickly if you have a problem and are able to refer you to an eye specialist at the hospital if necessary. **It is recommended that you visit your optometrist or optician every year.**

## **Visual Hallucinations.**

A visual hallucination seems the same as actually seeing something, but the 'something' is only in the mind. When these hallucinations occur as a result of sight loss, they are called Charles Bonnet Syndrome. They come and go unannounced and can last for just a few seconds or as long as a day or more.

Why do they occur? With our eyes open, the brain expects to receive and process a flood of complex electrical signals. In people with eye disease or a break in the visual pathways, what was once a flood may become a trickle. The visual areas of the brain then have little to do, so they invent pictures. These are visual hallucinations.

Charles Bonnet hallucinations can be simple unformed flashes of light, colours or shapes. However, many people see more elaborate forms such as geometrical grids and lattices or even landscaped gardens, animals, people, or faces with staring eyes.

Some people enjoy their hallucinations. However, they are more often an unwanted distraction, and can be frightening. They may make you doubt your sanity but remember - they are only a by-product of AMD.

There are ways to manage these hallucinations using exercises and distraction techniques. In some cases, medicines can be prescribed that are used to manage other conditions but may be effective with Charles Bonnet Syndrome.

## **Further information about your condition.**

To help you understand AMD and Charles Bonnet Syndrome, The **Macular Society** has a range of booklets at <https://www.macularsociety.org> and an **Advice and Information Service** on **0300 3030 111**.

# Benefits and Concessions.

This is a summary of the benefits and concessions available to you in Wales. In order to successfully claim many of these, it is helpful and sometimes essential that you provide evidence in the form of a Certificate of Vision Impairment or evidence of Registration as Sight Impaired (SI) or Severely Sight Impaired (SSI). You were issued with a Certificate of Vision Impairment (CVI) by the optometrist who diagnosed your eye condition.

Registration, on the other hand, is carried out by the Social Services Department of your Local Authority. You must be certified with a vision impairment prior to being registered with the Local Authority. The Local Authority must obtain your consent to include you on their register.

While Registration is voluntary, it is recommended if you would wish to obtain benefits or concessions.

Persons certified as SSI may be able to benefit from:

- Blind person's tax allowance
- Blue Badge Scheme – car parking (also refer below)
- Television licence fee reduction

Persons certified as SI **or** SSI may be able to benefit from:

- Free postage – “Articles for the blind”
- Free directory enquiries
- Free NHS eye examinations
- CEA card to bring a companion to a participating cinema for free
- Assessment by qualified Vision Rehabilitation Specialist

If you are certified as SI or SSI you may choose to consider yourself a 'disabled person'. As such, you are protected under the Equality Act 2010. As a Disabled Person you may be able to benefit from:

- Disabled Persons Railcard
- Free or reduced bus travel fare
- Blue Badge Scheme – car parking
- PIP - Personal Independence Payment
- Attendance Allowance
- Carer's Allowance
- Direct Payments
- Employment and Support Allowance
- Tax Credits for people on low income
- Housing Benefit
- [Disabled band reduction scheme]
- Council Tax Support
- Council Tax disability reduction
- Universal Credit
- Pension Credit
- Free and discounted tickets for a companion at theatres, galleries, or tourist attractions (numerous schemes depending on venue – Hynt, for example, for participating venues in Wales)

Please note that this information is for guidance only and is not an authoritative statement of the law.

For detailed information on these concessions, contact the **RNIB Helpline**:

- Call: **0303 123 9999**
- Email: **helpline@rnib.org.uk**
- Or say, "Alexa, call RNIB Helpline" to an Alexa enabled device.

The RNIB Helpline is available anytime from 8am-8pm on weekdays and 9am-1pm on Saturdays.

# Emotional impact of sight loss.

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

Macular Society's free, confidential **Counselling Service** offers support over the phone from a trained counsellor. Call their Advice and Information Service below for more information and to be referred for counselling.

You may feel better after an **initial telephone assessment**. You might have received all the information you need and feel that no further action is necessary.

On the other hand, you may benefit from **regular counselling sessions** with a counsellor. They will help lift your mood, reduce anxiety and recommend methods of coping with your diagnosis.

Sometimes formal counselling isn't required and a **telephone befriending service** could be more suitable. You may be managing well, but you could benefit from a regular friendly chat with a trained befriender.

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

Other national and regional organisations offer emotional support or counselling. For details please see the services available at **<http://wcb-ccd.org.uk/perspectif>**, contact **Wales Council of the Blind** on 029 2047 3954 or email **support@wcb-ccd.org.uk**

# Low Vision Service Wales.

You might be able to make many day-to-day activities easier by obtaining the right magnifiers and lighting to suit your particular needs. This free service can offer up to an hour-long appointment with a trained practitioner who will:

- measure your vision;
- discuss your eye condition(s) with you;
- discuss the difficulties that your low vision causes you; and
- help you to try out appropriate visual aids and prescribe suitable ones for you, free of charge.

This can take place at your high street optician, or you may be able to have a home visit. Your nearest services are available at <http://wcb-ccd.org.uk/perspectif>, or you can telephone **02921 500220** or email [low.vision@wales.nhs.uk](mailto:low.vision@wales.nhs.uk)

## Vision rehabilitation.

If you have given your consent, your council will contact you to talk about registration and assess what information and services could be useful. They may then arrange a specialist assessment aimed at establishing what support you may need. You will be referred to a Vision Rehabilitation Specialist who can work with you to:

- get about indoors and outdoors safely;
- improve your confidence with preparing meals;
- using appliances safely;
- using technology like computers and phones;
- find out about aids and adaptations that make life easier; and
- looking after yourself and your family.

They also provide information, training and advice for your friends, family and carers. Contact Wales Council of the Blind for details about your local service.

## **Education and employment.**

If you are in education or employment, support is available to help you to continue to study or work. If you're in school, college or university, there are sources of help such as the Disabled Students Allowance. If you are in employment, then Access to Work, for example, can provide practical support and equipment to help you start work, stay in work, move into self-employment, or start a business.

Contact the **RNIB Helpline** 0303 123 9999 or email:  
**helpline@rnib.org.uk**.

## **How can I get information, advice and support in my community?**

There is a range of services and support provided by charities and third sector organisations. They can help by giving information; practical support, such as travelling or shopping; clubs where you can meet other people with sight loss and share experiences; talking books and magazines. You can even get help to choose the right IT solution so that you can continue to read household bills or books.

Macular Society run numerous local peer support groups to help you beat the isolation of AMD by connecting you with other local people who know what you're going through. These groups offer support and companionship.

You can find details of local sight loss societies and national charities through <http://wcb-ccd.org.uk/perspectif> or contact **Wales Council of the Blind on (Cardiff) 029 20 473954**.