

## Low Vision Rehabilitation Services & Supports

During the early stages of vision loss, many patients can manage very adequately with visual tasks. However, as sight worsens some adaptation is required. Rehabilitation Services [RS] vary between countries and even between states and cities. RS are sometimes provided by hospitals, universities, charities (Non-Governmental Organisations – NGOs), state or commercial specialist service providers. A Skills of Daily Living (SDL) instructor will offer useful tips, training and coping techniques for the home or work place.

Reimbursement and funding issues are also not uniform. In Europe and America legislation assures low vision patients access to education and employment. In many other countries, if the services are available it is usually on a user-pays basis. Where a prescription is provided certain tax deductions may be allowed.

In general a comprehensive range of services and new technology increasingly offers assistance in making communication more accessible to people with low vision. The internet has brought access to assistance to many whilst international awareness of the necessity of legislation for rights for the disabled will in the future make life easier for AMD patients across the globe.

This document gives a brief overview of the types of support that may be available. Please contact your local NGOs and state rehabilitation service for referral to service providers in your area. Organisations of the blind and Retina International might also be able to assist.

**ASSISTIVE DEVICES** can be as simple as a black felt tipped pen or as complicated as a voice recognition computer programme that writes a letter for you. Some are optical and use lenses and prisms, while others use the latest computer technology to enhance print or convert it into audio text. In many cases common sense and imagination will be extremely useful:

- Illumination – spotlight work areas, use brighter globes.
- Contrast – use coloured coasters or back grounds.
- Size – use larger and bolder text.
- Tactile – use nail polish or hard setting putty to mark dials and devices

While some service providers offer a total and comprehensive service in other cases more than one provider will need to be seen. It is important to realise that no one assistive device can replace our complex vision to see objects in the distance as well as those up close, to see colours and in the dark, to detect depth, contrast and movement. Too many low vision patients expect a “one device fits all” solution while others buy too many devices and master none.

For an assistive device to be successful 3 important steps need to be followed:

- Accurate assessment
- Good choice of device
- Training in use of the device

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**OPTICAL DEVICES** - These are provided by a low vision therapist, usually an Optometrists who is specialised in Low Vision.

The first step will be careful assessment of your remaining vision. The 3 techniques used will incorporate size magnification, distance magnification and/or angular magnification.

Magnification devices can be spectacle mounted, hand held or free standing. Some magnifiers have a built-in light source while others have long flexible “goose necks”. An important point to remember is that the higher the magnification the shorter the viewing distance. Telescopic devices are useful for distance viewing and in some cases low vision patients with Bioptic devices are even allowed limited drivers licenses.

Reading machines can be standalone or linked to computers. A Closed Circuit Television Reader is a standalone instrument with a movable bed that magnifies text onto a TV type screen. Magnification and contrast are both variable and this is an excellent but expensive reading device. The latest models can also be linked to a computer for more versatility.

Small hand held readers with a built in screen and variable magnification are portable and thus very useful for a variety of tasks. The choice is endless and to ensure that you are prescribed the correct device visit a reputable service provider with a list of 3 or 4 of the most important visual tasks you need help with.

Ultraviolet light may increase the rate of degeneration in retinal conditions and definitely affects AMD patients. Therefore good UVa, UVb and blue light screening lenses offer not only protection but a decrease in glare sensitivity. These properties can be incorporated into your prescription lenses but the less expensive polarised or poly carbonate plastic lenses also offer excellent protection. Ask advice from your Optometrist or Low vision therapist.

**TECHNOLOGY-BASED ASSISTANCE** - The rapid advancement of application and miniaturisation of new technology has helped in the production of computer based programmes and devices for low vision patients. The range is vast and a visit to a specialised service provider is critical. To help understand what you should look at here are some general descriptions.

Screen Magnification and voice software: These programmes will convert normal text into an accessible format – either to a magnified version or a voice based version. Some programmes do both and people with progressive vision loss should consider a dual package. This software is expensive and a free trial version of the programme should be requested.

The newer versions of Windows have both elements built-in, look for the accessibility icon on your control panel. Desktop icons can be magnified and email text magnified or converted to voice. Contrast and size are both variable as is cursor size and trail, but key stroke substitution for most mouse tasks will save hours of cursor hunting. With AMD

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patients adequate training is often the most important and neglected key to the successful use of the device or programme.

Character Recognition: Text scanners bring text to the computer so that the above programmes can make the text available to the low vision patient. MOUSE type text scanners are portable and when coupled with a laptop with screen reading or magnification software will sometimes be all that a low vision patient needs in the work place. A fixed scanner at a work station could be available via a computer network to other workers and might be a more cost effective solution for employers.

A standalone Optical Character Recognition scanner converts text to speech. These are expensive but versatile machines for those without computer skills. Text can be saved and deleted.

Smart phones: The built-in and on apps that are now available are changing the lives of AMD patients. Many are free and can often replace technology that was only previously available as expensive electronic hand held devices. Voice technology ensures that AMD patients do not need to avoid smart phones with touch screens. Many smart phone manufacturers have specialized stores in big cities and will give free training if the smart phone is ordered via them from your service providers.

### **OTHER USEFUL DEVICES AND SERVICES**

Voice to text programmes need some training to recognize your voice but are of enormous benefit to people with poor key board skills. There is a definite market for the new electronic vision enhancing devices such as OrCam and eSight. They are expensive and you need to ensure that the vision improvement warrants the expense.

The implantable miniature telescope [IMT] also has some merit. This is a miniature telescope mounted into an intraocular lens that is inserted into the capsule of the lens of the eye. Discuss this with your Eye Care specialist and investigate thoroughly before taking a decision.

Talking Books: Libraries and Non-Governmental Organisations often provide this service. Formats vary and electronic readers such as in the Daisy format are very versatile and portable.

Tablets and iPads: Do investigate how these devices will assist you. Take the time to research and get trained. EBooks are being used by sighted people to such an extent that they are now really affordable.

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**MOBILITY** - Getting from point A to point B with poor vision is often the most frustrating complication for those with low vision. In areas with efficient and safe public transport this is easily overcome. The services of well informed, professional and patient rehabilitation officers can ensure that independence and accessibility can be maintained. Common sense is also necessary to ensure that obstacles are minimized for a stress free life. Always be aware of your surroundings and keep yourself safe!

Symbol Cane: This is a short fold down cane that is usually the first mobility aid used by people with decreasing vision. No training is required and although sometimes helpful for finding the edge of a step or similar simple tasks it is not really useful for people with very limited vision. Its main function is to alert other people to your loss of vision. Another way of doing this is to wear a low vision lapel badge. Either will often save you embarrassment and ridicule from the unsuspecting public.

Long Cane: The efficient and safe use of a long cane requires specialized training from a mobility instructor, but for people with severe loss of peripheral vision, this can be a liberating tool. Mobility Instructors are sometimes also SDL trainers and can help with orientation in both home and work place. Generally AMD patients retain good peripheral vision.

Guide Dog: This service is provided in most countries but lifestyle and cultural acceptance can be a contributing factor. Usually you are required to undergo long cane training before a guide dog will be provided. Training at the service provider and in your home environment is required.

**ECCENTRIC VIEWING** -Cone photoreceptor loss means that your central, fine focus vision is affected in AMD. The most concentrated area of cones is in the fovea, the very small central part of the macula.

Moving away from the fovea there may be areas where some cones survive. Identify this area of your “best vision” by drawing a clock face on a circle of paper. Mark the 3, 6, 9 and 12 o’clock points. Mark a dark dot in the centre. Testing one eye at a time, fixate on the central dot and decide which part of the clock you see most clearly.

Determine which is your best eye and train yourself to use this vision. Gaze to the left, right, up or down so that the object comes into that area of best vision. It will take some practice but the benefits are remarkable.

**DEVELOP GOOD HABITS** - be tidy and methodical. Do not leave obstacles lying about.

Store keys, remotes and other items in the same place, that way you will know where to find them, every time. Encourage family members to do the same.

Be practical: Peg your shoes together in pairs. Never face the embarrassment of going out with 2 different coloured shoes. Hang matching items of clothes on a single hanger.

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Mark stoves, washers, cookers etc. with a highlight marker or old nail varnish.

Be methodical: arrange cupboards, refrigerators etc. in sections and never deviate. Use bank bags filled with rice, sugar etc. attached to similar containers with sticky tape for quick identification.

Be disciplined with medication. Buy 30 tablet containers and get sighted friends or family members to arrange your medication into daily batches.

**FAMILY AND RELATIONSHIPS** - AMD is a very stressful and isolating condition. The normal steps of grieving for severe loss are often experienced. These are:

- Denial – Doctor shopping is common, hoping that you have been misdiagnosed.
- Bargaining - Faith healers and quacks are often sought for a miraculous cure.
- Anger- against God or your parents is common.
- Depression- this is often a serious and recurrent side effect of vision loss.
- Acceptance- only once this has been achieved can you take control of your life again.

With continual vision loss, aspects of this grief cycle are often repeated and professional help should be considered.

In advanced vision loss, depression, sleep deprivation and visual hallucinations [Charles Bonnet Syndrome (CBS)] are often experienced but not discussed by patients, afraid of being judged as mentally as well as visually impaired. Eye care professionals are now becoming more aware of this side-effect of AMD. CBS sometimes disappear within months of their appearance. Seek help.

**SERVICE PROVIDERS** - Some of the services that may be available to you locally are:

- Disability Grants – from state pension funds.
- Travel Assistance- free or special concessions from municipal or government agencies.
- Retinal Clinics or Retinal Specialists- where possible consult an eye specialist that has special knowledge of your condition and possible treatments.
- Low Vision clinics or practitioners.
- Access technology providers.
- Mobility Instruction & Guide Dogs.
- Counselling services
- Rehabilitation services- including computer training – from specialized service providers.
- Talking Books, Listeners libraries, large print - from NGOs or State libraries.
- Online news services or smart phone news apps.
- Travel Assistance- All airlines provide assistance which must be requested when reservations are made.
- Social Clubs & Sporting facilities - Blind Bowlers, Golfers, Chess, etc.
- Shopping - Most big supermarkets will provide assistance if pre- booked.

## **Low Vision Rehabilitation Services & Supports**

AMD patients need to work together to ensure adequate facilities are made available for them. If there is no AMD or retinal support group in your area why not start one. The benefits of such a group are:

- Mobilizing local resources for the benefit of AMD patients
- Creating Public Awareness of AMD
- Lobbying for government to fund more research into AMD
- Bringing international research findings to local patients

By becoming involved in finding solutions the person you most benefit is yourself.