

Making your home a better place to live with macular disease

A common concern for people who have macular disease (MD) is how the condition might make it harder to carry out daily tasks and live in their own home. But with the right support, some changes and adaptations, most people with MD can and do continue to enjoy living independently at home.

Some people choose to move to a house, flat or bungalow which they find more manageable, or which has linked care. If you are thinking about moving, it is important to weigh up the pros and cons of various options. Knowing about the different possibilities, and being clear about what features to look for, can help you make decisions that will best suit your changing circumstances.

In this brochure we briefly outline the main symptoms of MD and then consider what you can do to your home to make living with these more manageable. We describe the range of alternative housing options and offer suggestions about where to find more detailed information, advice and help for your particular situation. These notes are particularly for older people who may be considering their long term housing and care options anyway.

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Macular Disease symptoms

Macular disease is a condition that leads to the loss of the central part of vision. The macula is a small area of the retina at the back of the eye. When the cells in the macula deteriorate, this affects your eyesight in general – but to begin with it can affect it in a variety of specific ways. For example:

- Objects in front of you change size, or shape, or colour
- You can only see parts of pages for reading
- It is difficult seeing in bright light
- It is increasingly difficult to see when moving from a dark to a light room.

Some people also get hallucinations (seeing things that are not there). This is called Charles Bonnet Syndrome and might involve seeing patterns or objects such as animals.

With macular disease (MD), over time the central part of vision is lost but the side vision (peripheral vision) remains functional. Although there are unusual types of MD that affect younger adults, most MD is age-related (AMD). The two types of AMD are:

Wet Age-Related Macular Degeneration

New vessels form on the retina which 'bleed' and cause scarring. Loss of central vision can occur very rapidly and usually affects both eyes;

Dry Age-Related Macular Degeneration

As pigment cells under the retina die, vision becomes reduced. This can be very slow – sometimes over many years. A small proportion of people with dry AMD may also go on to develop wet AMD.

The Macular Disease Society and the Royal National Institute of Blind People have further details about different types of macular degeneration as well as other advice for living with sight loss – www.maculardisease.org and www.rnib.org.uk

Making your home easier to live in with Macular Disease

If you or someone you know has AMD there are a range of options for improving the home environment that can make living independently with sight loss more manageable. These ideas can be applied whether you stay in your current home or move to specialist or supported housing. They include considerations about:

- general design and layout
- lighting and heating
- safety and security
- going out and about
- gadgets and equipment

If you are considering later life housing and care options such as extra care or retirement housing, or residential care homes, then you may still find it useful to take these housing and design factors into account when making your choice.

If you live with and / or care for someone who has AMD, these design features and changes may also make it easier for you to continue to look after them.

Design and layout of your home

If you have early stage dry AMD, you have more time to plan and think ahead about where you live, consider how suitable it is and work out what you can do to prepare for gradual sight loss.

You will increasingly use your remaining peripheral vision to navigate around your home. This may be easier if you re-arrange the furniture to create clear pathways across rooms. Try to make it easier access the windows and doors and to reach the things you use most often in each room.

As well as maximising light (see section below), colour contrast is a key factor. Light walls and floors with darker furniture and fittings (eg coloured bedding against a pale carpet or vice versa) will make 'passage ways' clearer; strongly coloured doors and frames against a pale wall, and with a contrasting handle, will be easier to see. If redecorating, pale, plain matt paint on walls is best for maximising light and minimising glare.

Limiting trip hazards, including training yourself (and the people you live with) not to leave clutter on the floor is a small but essential step.

There are lots of gadgets and equipment – from clocks with large dials to stick on controls for washing machines. The Disabled Living Foundation’s website www.asksara.org.uk has a lot of information about products and gadgets to use in daily life, as do the RNIB and Macular Disease Society.

Major re-organisation of the layout of the home does have to be done carefully. If you have lived in the same place with limited changes for a long time, you may have deep seated memories or a ‘mind map’ of your home which enables you to find objects and move around relatively easily – gradual changes rather than a radical overhaul may be the best approach.

QUICK CHECK – DESIGN AND LAYOUT

Arrange furniture so you can safely move around	
If redecorating or re-arranging space, consider how to maximise colour contrast eg of doors vs walls, floor covering vs furniture	
Keep everyday items close to hand or stored where easy to reach	
Look into possible equipment and adaptations	

Design and layout of your home

Lighting

In order to make the most of your residual vision, good lighting in the home is crucial. This does not just mean putting in very bright lights everywhere – this can cause glare, shadows and ‘light pools’ which can result in falls. The principle is ‘the right light in the right place’. This means strong but even and glare-free central lighting for rooms combined with bright directional task lighting eg reading lamps by chairs, spot lights for kitchen work areas.

Maximising natural light is a useful starting point. This may be as simple as getting rid of net curtains (or at least using half size or very thin white ones if being overlooked is an issue), or putting in longer curtain poles to enable the curtains to be pulled back far enough to expose the whole window.

The Thomas Pocklington Trust offers a very useful guide to lighting in the home for people with sight loss www.pocklington-trust.org.uk/research/lighting, as do the Macular Disease Society noted above.

Touch-sensitive lights (activated by simply touching any part of the lamp base) can be particularly useful next to the bed. There are also 'motion-sensitive' lights which come on when you walk past them. Lights with movement sensors can be fitted to switch on when you get out of bed or when a person enters a room.

Being able to use lighting and heating controls is an important part of living independently. Think about the position of light switches, sockets and heating system control panels. Consider lowering light switches and raising sockets and choosing fittings that are a contrasting colour to the walls.

A cheap option is to put coloured tape around the edge of light fittings and to use contrasting colour extension cables from low sockets placed somewhere easier to reach, (although be careful to avoid trailing wires or overloading).

Heating

If you find the controls on electric and gas fires or central heating difficult to use, there may be alternative controls that can be positioned to make it easier for you to see and use. Either inquire with manufacturers or contact the specialist equipment and gadget agencies noted above.

QUICK CHECK – LIGHTING AND HEATING

Maximise level of natural light	
Install bright, even central lighting and well positioned task lights	
Have sockets and switches positioned at an easy to reach height and clearly marked	
Consider motion-sensitive and/or touch sensitive lights especially for use at night	
Alter heating controls to make them easier to see and use	

Safety and Security

It is worth thinking about how you might make your home safer and reduce accident risks, especially if you live alone.

In many areas, 'Home Safety and Security Check' services for older people are offered by voluntary organisations such as local Age UK or home improvement agencies – see Contacts section at the end.

• Staying safe at home

As a minimum install smoke alarms and carbon monoxide indicators. If testing and battery replacement are difficult install low maintenance and mains connected options that do not require batteries.

To reduce falls risk, cut clutter on the floors; remove loose rugs or frayed carpets; improve lighting; fit a second handrail on the stairs; put up grabrails (again, contrast colour) and clearly mark the edges of steps and stairs.

Occupational therapists (OTs) are the specialists who can advise about the equipment and adaptations that can help around the home. You may be able to get help and advice from an OT via your GP or Social Services, but this varies across the country.

There are also private OTs who can offer independent advice. You can find a properly trained and registered OT via the Independent Practice enquiry line on 0800 389 4873 or on www.cotss-ip.org.uk/directory/index.htm

• Telecare

There is an increasing range of devices that use a variety of sensors fitted around the home to monitor activity by the occupant or changes in 'normal' activity. The sensors are linked via a telephone line to a nominated person or a call centre. By monitoring the person's activities the system can detect potential problems and trigger an alarm to a relative, carer, neighbour or emergency services. This is broadly referred to as telecare.

Sensors can be used to detect factors such as:

- Normal daily activity eg. flushing the toilet, turning on taps, opening the fridge. If these actions don't take place at the 'normal' time a response can be made.

- Getting out of bed at night – bed occupancy sensors or pressure-mat sensors placed by the bed can activate an alarm when the person gets up in the night, eg to alert a carer.
- Floods – when sensors are fitted on skirting boards or floors in kitchens or bathrooms, if the taps are left running and cause a flood, the system will shut off the water and raise the alarm. Specially designed plugs can also be used to prevent floods from taps that have been left running.
- Extreme temperatures – sensors send a warning signal if a room temperature is very low or very high, or if the temperature suddenly goes up. In the kitchen, for example, this could detect a pan that has boiled dry. It can also detect if the temperature in a room is so low there may be a risk of hypothermia.
- Gas – sensors detect if someone forgets to turn the gas off, and a device will automatically shut this off and raise the alarm.
- Falls – sensors worn on the hip can detect the impact of a person falling.
- Unexpected absence from a bed or chair – if someone doesn't get up in the morning, a bed or chair occupancy system can raise an alarm.

There is also a growing range of equipment or Assistive Technology (AT) that can make independent day to day living easier.

Controlling who can come into and out of your home can be especially useful. One of the most commonly used pieces of equipment is a 'Keysafe'. This is a small, secure box which is fitted outside the home to contain the front door key. It can be opened by people, such as relatives and carers, who know the secure number code set for that specific safe. Fitting a door entry system is another (but more expensive) alternative.

QUICK CHECK – SAFETY AND SECURITY

Fit and maintain smoke alarms and carbon monoxide indicators	
Fit a KeySafe, entry phone system and/ or easy to manage locks	
Keep floors clear of clutter and loose or frayed rugs	
Find out about possible special equipment and adaptations	
Consider the range of telecare options	

Going out and about from your home

With AMD going out and about can become a challenge. Yet not getting out of your home can limit your sense of independence and your ability to do necessary tasks such as shopping or simply going out for pleasure.

One of the key considerations when it comes to where you live is whether you will be able to continue to get out and about if you currently rely on being able to drive and use a car. Location of your home may be the key consideration when making your longer term living plans.

However, there are special transport and mobility schemes for people with a wide range of disabilities, including sight loss. Your local council should have more information about what is available where you live, or look up www.shopmobilityuk.org or some of the other organisations listed below.

Gadgets and Equipment

There is an increasing range of gadgets and equipment to enable independence. RNIB sell a wide range of equipment. The Disabled Living Foundation's website www.asksara.org.uk has a lot of information about products to make day to day tasks more manageable.

There are around 40 Disabled Living Centres linked to AssistUK which have permanent exhibitions of equipment and offer professional advice about what may be of most use to you. To find your nearest centre see www.assist-uk.org

There are a number of 'independent living centres' where some equipment is on display and can be tried out. You can find your nearest centre using a search on the National Centre for Independent Living (NCIL) website <http://www.ncil.org.uk/categoryid21.html> NCIL are part of Disability Rights UK (www.disabilityrightsuk.org) and you can also call their Advice Line on 0845 026 4748.

Thinking about moving home

You may decide that having thought about the suitability of your current home, particularly if it is located somewhere that might make going out independently more difficult, moving might be a better option.

It is worth bearing in mind that many of the issues described above about living at home also apply to other housing options – such as the design and layout.

Your main housing options if you decide to move home include:

- A more suitable and better located 'ordinary' property (ie not one which has been built specially for older people) such as a bungalow or a flat that you might buy or rent.
- Special housing built for older people, such as retirement or sheltered housing. In some, but not all, of these types of accommodation help may be at hand if you need it. Some will be designed to make them easier for older people with health problems manage, such as having space for adaptations and equipment and with no steps or stairs.
- Specialist housing with 24 hour on-site care, such as extra care housing or an 'Assisted Living' apartment. These may be available to buy or to rent. There are also some specialist housing developments for people with sight loss.
- A care or nursing home.

Information about the pros, cons, costs and local availability of these housing options is available from the national, government backed, independent information and advice service *FirstStop Housing and Care Advice*.

Their website www.firststopcareadvice.org.uk lists in detail local specialist housing developments (both for sale and rent) as well as related services. They produce brochures about housing and care options and offer a free telephone helpline 0800 377 70 70.

Wherever you choose to live, you might need help with day to day living, such as washing, dressing, cleaning and so on. FirstStop, as well as some of the organisations listed below, can offer information about how to find and pay for the care you need.

Sources of Related Advice and Information

The Macular Disease Society

0845 241 2041

www.maculardisease.org

Royal National Institute of Blind People

0303 123 9999

www.rnib.org.uk

Carers

Carers UK

Advice line 0808 808 7777

www.carersuk.org

Older People

AgeUK

Advice line 0800 169 6565

www.ageuk.org.uk

Housing and Care Information for Older People

FirstStop

Advice line 0800 377 70 70

www.firststopcareadvice.org.uk

Home Repairs and Adaptations Services

Foundations (for home improvement agencies)

Telephone 08458 645210

wwwFOUNDATIONS.org.uk

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