

Making your home a better place to live with macular disease



Who is the guide for?

This guide is for people with macular disease (often referred to as macular degeneration) and their carers

It focuses on the impact of macular disease on daily living at home aiming to make life easier so that you can continue to live independently and do the things you want to do.

It is also aimed at informing organisations providing a range of services for older people and points them in the direction of simple, and often low-cost, adaptations that can make a big difference to people's lives, as well as signposting to the organisations that can help.

Separate guides are available for people with other health conditions. These will be helpful for those who may have several long-term conditions. There is also a guide for people with dementia.

<https://silverlinksprogramme.wordpress.com/resources-for-older-people/>

By making the home safer to negotiate the lives of carers too can be made significantly easier.

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How can this guide help you or a family member?

If you or your partner or family member have been diagnosed with macular disease there are several things you could do to improve your home environment to enjoy life and live life to the full.

These ideas can be considered whether you stay in your current home or move to specialist or supported housing.

They include considerations about:

- general design and layout to support a good life at home
- lighting and heating
- safety, security and technology
- gadgets and equipment
- going out and about.

Where appropriate there is a link to further advice. There is also a section on moving options should this be an option you want to consider.

Symptoms of macular disease

Macular disease (MD) 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, 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 Society – see <https://www.macularsociety.org/> and the Royal National Institute of Blind People – see <http://www.rnib.org.uk/> have further details about different types of macular degeneration as well as other advice for living with sight loss.



Our aim in this guide is to offer options to minimise impact so that you can live comfortably and well at home. For ease of reference we have identified changes that focus on: -

- general mobility
- compensating for any reduced vision and improve safety
- keeping warm.

Financial help with repairs, improvements and adaptations to your home

If you are on a limited income and have been affected by conditions that restrict your movement or make it difficult or unsafe to move about your home, you may be entitled to some help with repairs, adaptations and equipment in your home.

A Disabled Facilities Grant (DFG) is available from the local council if you are eligible and there may be other housing grants available. DFG pays for essential home adaptations and is mandatory and means tested. The maximum grant is £30,000 with average grants of £6,500. Some councils will have smaller grants for essential repairs or heating but this varies locally so you need to contact your local council to find out what is available.

Disability Rights UK at <https://www.disabilityrightsuk.org/housing-grants?onOff=OFF>

Age UK at http://www.ageuk.org.uk/BrandPartnerGlobal/portsmouthVPP/Documents/FS13%20Funding%20repairs,%20improvements%20and%20adaptations%20July%202010_fcs.pdf

and

http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS42_Disability_equipment_and_home_adaptations_fcs.pdf?dtrk=true



The home and garden

How safe or otherwise is your home?

One idea is to check your home room by room, as well as any outside areas, listing features that might be awkward now or that you imagine might be hard in the future if your condition deteriorates. Look for features that make it hard to move around, carry out daily tasks like food preparation, look after yourself (such as washing and dressing), looking after the home keeping it clean and tidy and, of paramount importance, enabling you to do the things you enjoy most at home. Simple adaptations or changes might make a big difference to you.

Design and layout

General mobility - create the space to move around and prevent falls

If you have early stage dry macular disease, 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:

- Make pathways through the home and garden to navigate better rearranging the furniture to create clear pathways across rooms to make it easier to access the windows and doors and to reach the things you use most often in each room.

Compensating for any reduced vision and improve safety

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.

- Colour contrast can help such as light walls and floors with darker furniture and stronger coloured doors to make 'passageways' clearer. A contrasting colour handle will help. If re-decorating, pale, plain matt paint on walls is best for maximising light and minimising glare.
- Trip hazards should be limited so areas should be clear of clutter and cables with non-slip floors and no loose carpets. Ensure there are non-slip mats in the bathroom area.
- There is a range of equipment and gadgets that may help with navigation and daily living including larger TV remotes and telephones, simple manageable tin openers, floor pickers, and a range of kitchen/bathroom appliances.

The Disabled Living Foundation's website <http://www.dlf.org.uk/content/asksara> has a lot of information about products and gadgets to use in daily life, as do the RNIB <http://www.rnib.org.uk> and Macular Society <https://www.macularsociety.org/> with a guide on Daily Living Skills <https://www.macularsociety.org/sites/default/files/resource/Macular%20Society%20Daily%20Living%20Skills%20accessible%20pdf%20MS004%200617.pdf> Audio version <https://www.macularsociety.org/sites/default/files/downloads/Daily%20Living%20Skills%20CD.mp3>

Housing Guide for People with Sight Loss Thomas Pocklington trust <http://www.pocklington-trust.org.uk/guide-finding-home-visually-impaired-people1/>

Quick checklist: Design and layout

Tick box

Make pathways through the home and garden to navigate better, create pathways to reach windows, doors and the things you use most often in each room.

Create colour contrast such as light walls and floors with darker furniture and stronger coloured doors

Limit trip hazards, avoid leaving clutter on the floor and remove rugs that may cause trips

Consider gadgets and equipments that might help with daily living

Lighting and heating

Compensate for reduced vision and improve navigation

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 as this can cause glare, shadows and 'light pools' which can result in falls. The principle is 'the right light in the right place.'

Consider: -

- Strong, even and glare free central lighting for rooms is helpful combined with bright directional task lighting e.g. reading lamps by chairs and spot lights for kitchen work areas.
- Maximising natural light: 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.
- Using touch or motion sensitive lights especially next to the bed, over steps or stairs, or at room entrances.
- Using rechargeable wall lights might also help.
- The location of lighting is as important as the light source to avoid shadows and glare.
- Leaving lights on in bathrooms or toilets overnight if helpful.
- The position of light switches, sockets and heating system control panels for ease of access.
- Choosing fittings that are a contrasting colour to the walls.

Lighting Solutions Guide RNIB

<http://www.rnib.org.uk/sites/default/files/Lighting%20Solutions%20guide%202013-14.pdf>



Keeping warm

Make sure the house is warm and dry so as not to aggravate your condition. A home which is warm and dry, especially in colder weather, is critical for people with all long-term health conditions.

- Maintain a higher background level of warmth throughout all the parts of the home that you use daily if you can to prevent major fluctuations in temperature.
- Moving out of a warm, well heated living room into a cold hall, kitchen or bedroom can be particularly risky.

- Make sure your home is well insulated and draughtproof but good ventilation is required if solid fuel (coal or wood) fires are used. Check if there is any damp or condensation.
- It is also important to ensure that chimneys and flues are in good condition and swept regularly.

Winter wrapped up from Age UK http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIG27_Winter_wrapped_up_inf.pdf?dtrk=true

Living Safely and Well at Home from Care and Repair England

<http://careandrepair-england.org.uk/wp-content/uploads/2014/12/Revised-LIVING-SAFELY-Lft.pdf>

For advice on damp, condensation and insulation options contact your local Home Improvement Agency. See Organisations that can help on Page 17.

The Energy Savings Trust offers advice on energy efficiency

<http://www.energysavingtrust.org.uk/>

Quick checklist: **Lighting and heating**

Tick box

Consider strong, even and glare free central lighting combined with bright directional task lighting

Maximize natural light and avoid shadows and glare through light location

Use touch or motion sensitive lights where appropriate

Consider using rechargeable wall lights

Leave lights on in bathrooms or toilets overnight as appropriate

Position light switches, sockets and heating system control panels for ease of access

Choose fittings that are a contrasting colour to the walls

Keep the home warm and well insulated and seek advice on help with heating and insulation

Deal with damp and condensation by seeking advice

Ensure that chimneys and flues are in good condition and swept regularly

Safety, security and technology

General mobility – create the space to move around and prevent falls

With any health condition it is worth thinking about how you might make your home safer, especially if you live alone.

Falls can be a hazard as you get older. The risk of falls and accidents can increase, so it is worth thinking about how you might make your home safer. Simple measures such as keeping rooms free of general clutter on the floors, removing loose rugs or frayed carpets and having good lighting can help reduce risk of falls.

Many falls happen on steps and stairs. Fitting a second handrail on the stairs, putting up grab rails by steps and clearly marking the edges of steps and stairs are just some of the measures worth taking sooner rather than later.

Bathrooms are another major falls and accident risk area. Grab rails and a toilet seat riser can help with being unsteady when going from sitting to standing. No longer being able to use a bath safely is one of the main reasons that older people seek help with adapting their home. Installing a level access shower or wet room as soon as possible to learn to use this equipment can both enable you to look after yourself for longer, as well as making it easier for carers later on.

Occupational Therapists (OTs) are the main professionals to advise and you could also try your local Home Improvement Agency (HIA) if you have one. Contact Foundations <http://www.foundations.uk.com/> for your local HIA. See list of organisations on page 15

Occupational Therapy services are available free of charge from the NHS and social services so contact social services in the first instance. If it takes time for an OT to visit, try the Disabled Living Foundation (DLF) <http://www.dlf.org.uk/?gclid=CMK7gvL159UCFQS3Gwoda7EOKA> for information on the options to consider.

Independent Occupational Therapists usually provide services that are not available from the NHS or social services and/or have no waiting lists. You can find a properly trained and registered OT via the College of Occupational Therapists <https://www.cotss-ip.org.uk/find#!location=SE5+9AW&service=0>. You can also call the Professional Practice Enquiries Service at the Royal College of Occupational Therapists 020 7450 2330

Compensate for any reduced vision and improve safety

To provide a safe home better lighting, as well the installation of low maintenance or mains connected smoke alarms and carbon monoxide indicators, will benefit everyone.

There is a growing range of equipment or Assistive Technology (AT) that can make independent day to day living easier by providing help to enable washing, dressing, cooking, eating and other daily activities or to offer greater security by the provision of an alarm system with links to people outside the home that can offer help in an emergency. There are also many developing technologies that help people to live their lives to the full at home offering help with communication, creativity and daily activities.

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 often 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.

Technology is changing rapidly with more devices available for communications and support and a rapidly changing landscape. Where appropriate we have offered a link to guides and organisations that can help.

Consider if an alarm system, telecare and assistive technology options might help you with daily living and offer you some reassurance at home.

- Alarm systems are activated by the person and are linked to a centre or nominated person.
- Telecare systems generally have sensors that monitor activities and alert a call centre or nominated person in response to lack of activity. Sensors might cover such areas as bed occupancy, flush use, fridge opening which assess if the person is mobile. Other sensors might include flood and extreme temperatures, gas sensors and also falls sensors detecting if a person falls.
- Assistive technology and equipment covers a range of products and equipment that help make independent living easier such as help with washing, dressing, cooking and eating as well as other daily activities.
- Safety and security may also be enhanced by a key safe or, a costlier option, a door entry system. Key safes can sometimes be provided by the local council if you install an alarm. The key is put outside in the safe and accessed by a code. Door entry systems can enable visitors to open the door without the host having to get up.

In some areas, a home safety and security check is offered – contact your local Home Improvement Agency via Foundations or your local Age UK

Information on alarms and telecare is available from NHS Choices – See <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/telecare-alarms.aspx>

and from the Disabled Living Foundation (DLF) Ask Sara <http://www.dlf.org.uk/content/asksara>

Independent Age have a guide to Assistive Technology <https://www.independentage.org/sites/default/files/2016-12/Factsheet-Technology-to-help-you-at-home-larger-text-version.pdf>

Technical hub RNIB <http://www.rnib.org.uk/practical-help/technology-hub>

Assistive and Inclusive home technology for people with sight loss Thomas Pocklington Trust http://www.pocklington-trust.org.uk/wp-content/uploads/2016/07/AIT-Guide_Accessible.pdf



Quick checklist: **Safety, security and technology**

Tick box

Keep rooms free from clutter and remove loose rugs and frayed carpets

Ensure good lighting, especially over steps and stairs

Fit a second handrail up the stairway and grab rails by steps

Mark the edges of steps and stairs

Consider installing a level access shower or wet room

Consider a toilet riser and grab rails in the bathroom

Install low maintenance or mains connected smoke and carbon monoxide alarms to avoid having to change batteries

Consider if an alarm system, telecare and assistive technology options might help you with daily living



Gadgets and equipment

What is available and appropriate for you

There is an increasing range of gadgets and equipment available to enable people to remain independent at home. For detailed information, you can use Disabled Living Foundation's website – Ask Sara <http://www.dlf.org.uk/content/asksara> which has a great deal of information about what is available across a range of activities at home and includes details of suppliers. Some of the areas covered include products that will support you in using the bathroom, kitchen and bedroom, stairs and garden and home entrance.

Contact Ask Sara <http://www.dlf.org.uk/content/asksara> for more specialist information about daily living products

Information on everyday living RNIB <http://www.rnib.org.uk/information-everyday-living/home-and-leisure>

Daily Living Skills Macular Society <https://www.macularsociety.org/> with a guide on <https://www.macularsociety.org/sites/default/files/resource/Macular%20Society%20Daily%20Living%20Skills%20accessible%20pdf%20M5004%200617.pdf> Audio version <https://www.macularsociety.org/sites/default/files/downloads/Daily%20Living%20Skills%20CD.mp3>

Centres to try

In some areas of the country there are **Disabled Living Centres** and **Centres for Independent Living** where you can try equipment and products. Contact your local council to find out if you have one in your area.

Getting out and about

With macular disease 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.

Think about access to and from your home and in the garden so consider ramps and grab rails where feasible.

An Occupational Therapist or Home Improvement Agency can advise. See Organisations that can help on Page 15.

If you, or your friends and carers, need help with transport with a car then car parking will be important to you and specifically those spaces available for disabled drivers if you become entitled to a blue badge.

<https://www.gov.uk/apply-blue-badge>

Thinking about moving home

You may decide that having thought about the suitability of your current home, 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. Because a property has been built for older people does not automatically make it well suited for a person with macular disease.

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 people with limited mobility to manage, such as having wide doorways, 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 specific conditions such as 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, independent information and advice service *FirstStop Housing and Care Advice*.

Their website <http://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. The Thomas Pocklington Trust also has a guide called a Housing Guide for People with Sight Loss <http://www.pocklington-trust.org.uk/guide-finding-home-visually-impaired-people1/>

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.

Organisations that can help

Age UK – <http://www.ageuk.org.uk/> Tel: 0800 055 6112

Carers UK – www.carersuk.org Advice Line: 0808 808 7777

Disabled Living Foundation – <http://www.dlf.org.uk/>

Tel: 0300 999 0004

Disability Rights UK – <http://disabilityrightsuk.org/>

- General Enquiries: 0203 687 0779
- Personal Budgets Helpline: 0300 995 0404
- The Equality Advisory Support Service helpline: 0808 800 0082

First Stop – Information about the pros, cons, costs and local availability of housing and care options is available.

www.firststopcareadvice.org.uk

Home Improvement Agencies via **Foundations** their national body –

<http://www.foundations.uk.com/>

Tel: 0300 124 0315

Independent Age – <https://www.independentage.org/>

Tel: 0800 319 6789

NHS Choices – <http://www.nhs.uk/pages/home.aspx>

Occupational Therapists work with people to enable them to achieve health, wellbeing and life satisfaction through participation in activities that mean something to them, retaining independence

Occupational therapy services are available free of charge from the NHS and social services so contact social services in the first instance. If it takes time for an OT to visit, try the Disabled Living Foundation (DLF) <http://www.dlf.org.uk/> for information on the options to consider.

Independent occupational therapists usually provide services that are not available from the NHS or social services and/or have no waiting lists. You can find a properly trained and registered OT via the College of Occupational Therapists <https://www.cotss-ip.org.uk/find#!location=SE5+9AW&service=0>. You can also call the Professional Practice Enquiries Service at the Royal College of Occupational Therapists 020 7450 2330

Silverlinks run by Care & Repair England is about creating networks of mutual support to enable older people to make informed decisions about their housing and related care. It provides useful information about housing and care options including a 'teach yourself' booklet <https://silverlinksprogramme.wordpress.com/>
Tel: 0115 950 6500

The Macular Society – www.macularsociety.org
Helpline: 0300 3030 111

Royal National Institute of Blind People – www.rnib.org.uk
0303 123 9999

Thomas Pocklington Trust – www.pocklington-trust.org.uk
0208 9950880

Useful guides

These guides offer advice and support for independent living

Alarms and technology

Alarms and telecare from NHS Choices
<http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/telecare-alarms.aspx>

Assistive Technology guide from Independent Age
<https://www.independentage.org/sites/default/files/2016-12/Factsheet-Technology-to-help-you-at-home-larger-text-version.pdf>

Assistive and Inclusive technology for people with sight loss Thomas Pocklington Trust http://www.pocklington-trust.org.uk/wp-content/uploads/2016/07/AIT-Guide_Accessible.pdf

General

A practical guide to healthy ageing Age UK/NHS England
<https://www.england.nhs.uk/wp-content/uploads/2015/09/hlthy-ageing-brochr.pdf>

Living Safely and Well at Home from Care& Repair England
<http://careandrepair-england.org.uk/wp-content/uploads/2014/12/Revised-LIVING-SAFELY-Lft.pdf>

Thinking Ahead: Housing, Care and Related Finance in Later Life from Silverlinks
<https://silverlinksprogramme.wordpress.com/resources-for-older-people/>

Winter wrapped up from Age UK
http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIG27_Winter_wrapped_up_inf.pdf?dtrk=true

Sight loss

Daily Living Skills: the Macular Society

<https://www.macularsociety.org/sites/default/files/resource/Macular%20Society%20Daily%20Living%20Skills%20accessible%20pdf%20MS004%200617.pdf>

Daily Living Skills Audio version <https://www.macularsociety.org/sites/default/files/downloads/Daily%20Living%20Skills%20CD.mp3>

Technical hub RNIB <http://www.rnib.org.uk/practical-help/technology-hub>

Information for home and leisure: RNIB

<http://www.rnib.org.uk/information-everyday-living/home-and-leisure>

Lighting Solutions Guide RNIB

<http://www.rnib.org.uk/sites/default/files/Lighting%20Solutions%20guide%202013-14.pdf>

Housing Guide for People with Sight loss Thomas Pocklington Trust

<http://www.pocklington-trust.org.uk/guide-finding-home-visually-impaired-people1/>

This guide has been produced with help from the Older People's Housing Champions network and The Elders Council of Newcastle Reader's Group



The Older People's Housing Champions is a network of older activists who support action by older people's groups to improve housing and related services for an ageing population across England.

www.housingactionblog.wordpress.com



The Elders Council of Newcastle is a group of people who are committed to having a say about how to make Newcastle a great city in which to grow old. We do this in a variety of ways - peer research, arts projects, focus groups and regular meetings with service providers and policymakers.

www.elderscouncil.org.uk



Care & Repair England is an independent charitable organisation which aims to improve older people's housing. It is a Registered Society with Charitable Status Reg No 25121R.

Head Office: The Renewal Trust Business Centre,
3 Hawksworth Street, Nottingham NG3 2EG

www.careandrepair-england.org.uk Twitter @cr_england



Silverlinks is about creating networks of mutual support to enable older people to make informed decisions about their housing & related care.

<https://silverlinksprogramme.wordpress.com/> Twitter @_Silverlinks

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Published 2017

Designed by The Design Box, Leeds