

A photograph of two elderly women with short, wavy grey hair. They are shown from the chest up, facing each other and embracing. The woman on the left is wearing a bright pink top and glasses. The woman on the right is wearing a teal short-sleeved top with white trim on the sleeves. They are both smiling and looking at each other. The background is a softly blurred indoor setting with warm lighting.

Hints and tips for carers

Foreword

By Mark O'Donnell



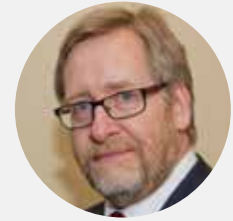
We are delighted to host this joint event with Scottish Care. In Scotland, one in five people aged 75 and over, and one in two people aged 90 and over, are living with sight loss and overall sight loss is projected to double in the next few decades due to our ageing population. It is therefore more urgent than ever that the care sector and its numerous partners collaborate and plan now for how this huge human and societal challenge can be addressed. As Scotland's only specialist provider of care homes for people with sight loss, Royal Blind has a wealth of experience in this area. We know only too well the extra challenges sight loss poses to person-centred care – often underestimated – on top of an already complex burden of care which dementia, frailty, multimorbidity and palliative care presents. We are very grateful to Scottish Care – with all of their own expertise and passion – for recognising the importance of these issues and helping us to raise awareness and to share innovation and best practice.

M. O'Donnell

Mark O'Donnell
Chief Executive, Royal Blind

Foreword

By Dr Donald Macaskill



To be included means to feel valued and wanted, affirmed in who you are as a person.

Human rights are about enabling people to achieve inclusion. Yet unfortunately there are too many who are excluded including many individuals who live with vision impairment. People around them, including those who might care for them, fear to do the wrong thing and so end up doing nothing. People are worried about saying the wrong thing, so they end up in silence.

I am delighted that this marvellous booklet has been written. It is about ensuring that we can all have much greater confidence in supporting people with vision impairments to live better lives and thus to achieve their human rights. It is packed full with common sense insights which will improve the practice of the thousands of women and men who support and care for those with vision impairments.

A handwritten signature in black ink that reads "Donald Macaskill". The signature is written in a cursive, slightly slanted style.

Dr Donald Macaskill
Chief Executive Officer, Scottish Care

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Sight loss

Sight loss affects a person's engagement in everyday life and is often a hidden disability in older people.

The aim of this booklet is to give you some hints and tips for supporting people who have sight loss, and some information about the most common eye conditions.

The residents and staff of Royal Blind's care homes, Braeside House and Jenny's Well, contributed to this booklet and were instrumental in helping to ensure we acknowledged and understood what helps them. They were very keen to share their expertise!

Sight loss statistics

- One in nine people over the age of 60 have a vision impairment.
- One in five people over the age of 75 have a vision impairment.
- Half of people over the age of 90 have a vision impairment.
- Two-thirds of people with diabetes have some form of retinopathy.
- 250,000 people live with sight loss and dementia in the UK.
- Every day 250 people start to lose their sight.
- People who are vision impaired are also likely to be living with three or more other health conditions.

Aids and equipment

There are many aids out there that can make the difference to a person with sight loss.

Magnifiers and lighting are particularly important, especially for those who have conditions that affect the central vision, like macular degeneration. Accessing and using these pieces of equipment can help people maintain their independence and reduce their reliance on others.



Adjustable lamps



Hand-held magnifier



Talking clock



Non slip colourful mats



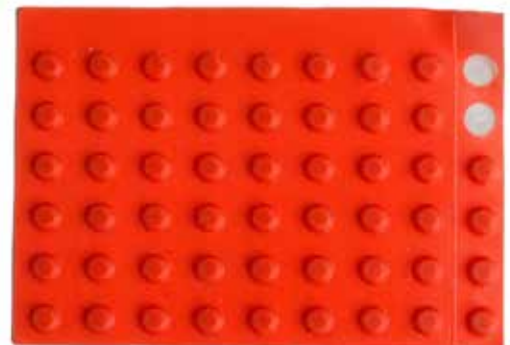
Liquid level indicator



Memo voice recorder



Large face watch/
talking watch



Bumpons

Eating and drinking

These tips can make the difference between someone requiring physical support to eat and drink to managing on their own, giving them control over their menu choices and how they eat.

- **Colour contrast:** Think bright and bold. If you use white plates, put a coloured mat underneath. If the food is mainly white, use a dark plate.



- **Keep everything in its place:** Guide the resident's hands to the object to help them identify it.
 - **Get to know residents' preferences:** For example, Mary likes her apple juice on the top left-hand side.
 - **Use a 'clock' system:** Place food in relation to numbers on a clock face. Turn the plate if needed and always think about the resident's vision impairment.
 - **Reassure:** Residents may feel embarrassed when it comes to 'missing their mouth'. Reassure them and make sure they have a napkin.
 - **Explain:** Speak about the food choices and cut up food if asked.
- **Avoid shiny things:** They can cause glare and reduce any remaining vision.
 - **Use square tables:** Defined edges make things easier to feel.

Remember:

Clear used things out of the way.

Make sure I know where my food and drink is before you leave.

Explain what is on my plate and the area around it.

Communicate with the residents and ensure a calm dining experience.

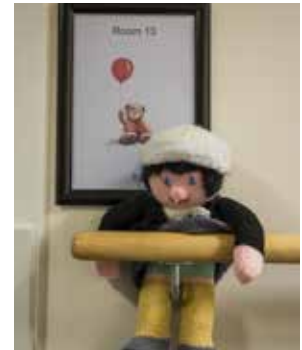


Mobility

Several studies have found that fear of falling led to older people with sight loss restricting their mobility.

There is often a risk averse approach from families and staff and they can discourage people from mobilising independently.

- **Wayfinding:** Work with the person to identify their most frequent routes – toilet, dining room, sitting room. Pick a route to practise and gradually reduce the support as their confidence increases. Often people will mentally map their route e.g. “If I take 14 steps I will be at my door and then I turn left to get to the dining room.”
- **Keep areas clear and clutter free:** Ensure nothing is out of place. If they have a cluttered environment and it is familiar to them, do not feel you have to declutter it.
- **Using wheelchairs:** There is no reason why a person cannot independently use a wheelchair as most will have some residual vision. The same rules apply as with mobilising.
- **Create an identifier for their room:** Use a cuddly toy, a colour contrast, or their name in bright bold letters. Something they can reach out and touch. This will help build the resident’s confidence in finding their own way.
- **Offer a ‘commentary’:** When a resident is mobilising (walking or being pushed in a chair) talk them through the process. This allows the resident to know their environment and any hazards approaching, and can ease fears of falling.



Remember:

When I can hear your voice, it makes me feel less anxious.

Hearing a familiar voice reassures me that you are close.

Give me the space to be independent.



Communication

Communication is key to everything we do.

Ensuring that we are clear in our explanations and taking the appropriate time to communicate can help reduce the loneliness, isolation and anxiety that people who are sight impaired can experience.

- **Explain, describe and reassure:** Always remember that a vision impaired person can find it scary if you approach them without talking to them. Explain each bit of care as you go, especially if you are using a hoist.
- **Speak clearly and slowly:** Use detail and explain what you are doing, be verbally vocal.



- **Introduce yourself:** Wait to make sure they are aware you are there. Sometimes you can use a code/particular knock/sing a song at the door so they can identify you. Assess the person's vision and approach from their 'good' side.

Remember:

Introduce me to whomever I am sitting beside so I can talk to that person or even know that there is someone else there.

Tell me when you leave me.

Staff should explain who they are every time they speak to me.

Ask me if I can manage that – do not presume I cannot.

Tell me where things are and guide my hands to the objects in front of me.



Maintaining independence

It is important that everyone is supported to be independent to ensure that they maintain control of their life and live the life they wish.

Having a vision impairment often means everyday tasks take longer and it is sometimes easier and quicker for well-meaning staff to over help. Taking a little bit of extra time can make a huge difference for older people with sight loss.

- **Offer choices:** What colour to wear, trousers or skirt, what jewellery, colour of nail polish, many residents will know exactly what is in their wardrobe and can tell you what they want to wear.
 - **Describe the outfit:** Let them feel the clothes to help them choose.
 - **Keep their possessions in the same place:** Don't move it without telling them.
 - **Encourage independence:** Get them to do their own care even if it takes longer, guide and supervise. Don't do it for them.
 - **Aids:** Consider what aids and technology might help.
- **Use a person-centred approach:** Think about what the individual might like and enjoy doing. Observation of how the resident orientates him or herself to their environment helps the carer understand their needs, habits and ways in their routine.
 - **Use colour contrast:** Use dark towels, dark plates under light food, put medication on a contrasting colour – small things can change dependence to independence.



Remember:

I have been able to see for most of my life. I may not see colours anymore but I can mostly remember.

Staff always ask me to do things before they try to help me.

Time is required and often prompting.

Make sure everything is within reach and use my hand to touch items so I know where to reach.



Activities

It can be challenging for staff to think of ways to ensure that older people who are vision impaired are involved in activities in care environments.

Often they find it difficult to be involved in some of the usual activities and do not participate, leading to loneliness and isolation. It is important to know that everything is possible; you just have to change things up a bit.

- **Alternative formats:** Many board games come in large print versions or are tactile.
- **Be descriptive:** If you have someone who is vision impaired be more descriptive, and make best use of his or her other senses.
- **Adapt:** Often a resident can manage what they were doing before with some additional help e.g. they can still paint but may use a magnifier.
- **Use sound:** For example when bowling, use a ball with a bell inside or bang a stick to indicate the direction you want the resident to aim for.



Remember:

There are plenty of board games I can still play – it's not all dominoes and bingo!

Get to know my line of vision and sit me where I get the best view.

I can use my voice to control an iPad or Alexa.

Large groups can be overwhelming for me.



Anxiety

Older people who are vision impaired are more than twice as likely to experience depression and anxiety symptoms as those without.

Loneliness and isolation can be a big factor as people who are vision impaired can lose their confidence.

- **Confidence-building:** By building up their confidence and self-esteem, people can become more confident and more willing to interact with others, particularly in a care home environment.
- **Continuity is key:** Keeping things consistent can help residents feel less anxious – including staffing and preferred routine.
- **Don't overload:** A lot of instructions can confuse the resident and make them more anxious, allow them time to explain what is making them anxious so you can help.



Remember:

Consider your tone of voice when you speak to me. Use a calm voice, and speak slowly and clearly.

Give me a reassuring pat to let me know things are okay.

I can sense your calm manner and it calms me when I feel anxious.



Key points to remember

1
Take your time
and be patient.

2
Be creative and work together
to find the best solution. Keep
experimenting until you get it
right for that person. Everyone
has their own way of coping,
and adopts their own
techniques. Learn from them!

3
Explain, Describe
and Reassure



Remember:

Tell me who you are every time you speak to me and tell me when you leave.

If you are not sure what to do - ask me!

Encourage my choices and independence.

I probably do have some sight.

Explain what you are going to do while you are helping me.

Tell me where things are and don't move them around.

Make every interaction you have with me count.

Get to know me – ask me or my family what works for me in relation to my sight loss.

Macular Degeneration

Age-related macular degeneration (AMD) is a painless eye condition that causes you to lose central vision, usually in both eyes.

AMD does not cause total blindness but can make everyday living quite challenging. It makes things like reading, driving, watching TV and recognising people difficult.

There are two types of AMD – ‘wet’ and ‘dry’. The majority of those who have AMD have the dry form.

Dry AMD develops over a longer period and often people do not notice the initial deterioration.

Wet AMD can cause sight to deteriorate rapidly – over a period of weeks or months.

In wet AMD too much Vascular Endothelial Growth Factor (VEGF) is produced in the eye, this causes the growth of unhealthy blood vessels.



Normal vision



Macular Degeneration



Treatment options

- There is no treatment for dry AMD. There are aids and equipment that can help.
- Wet AMD can be treated using 'Anti-VEGF' drugs. VEGF (Vascular Endothelial Growth Factor) is the chemical in the body responsible for the development of healthy blood vessels. The drug is injected into the eye and works by blocking the production of VEGF.

Risk factors

- Age
- Smoking
- Family history
- Obesity
- High blood pressure

Glaucoma

Glaucoma is a common eye condition. Two percent of the population in the UK have glaucoma and one in 10 people over the age of 75 have this condition.

The most common form is primary open angle glaucoma, which develops slowly over a long period.

It is caused by fluid building up in the front part of the eye as the drainage channels become blocked. This increases the pressure in the eye and causes damage to the optic nerve. This means that the information that is relayed to the brain is incomplete.

Glaucoma does not usually cause any symptoms to begin with. It tends to develop slowly over many years and affects the edges of your vision (peripheral vision) first.

Glaucoma can lead to loss of vision if it is not diagnosed and treated early. Glaucoma does not present with any symptoms in the early stages and tends to be identified at routine eye tests.

It can affect people of all ages but is most common in adults in their 70s and 80s.

It is not possible to reverse any loss of vision that occurred before glaucoma was diagnosed, but treatment can help stop vision getting worse.



Normal vision



Glaucoma



Treatment options

- Eye drops to reduce the pressure in your eyes.
- Laser treatment to open up the blocked drainage tubes or reduce the production of fluid in your eyes.
- Surgery to improve the drainage of fluid.
- Treatment and monitoring are usually lifelong.

Risk factors

- Age
- Ethnicity
- Family history
- Other medical conditions

Cataracts

A cataract is clouding or opacity of the lens inside the eye.

The lens inside the eye should be clear. The lens helps to focus the light rays to the retina at the back of the eye and this sends messages to the brain to allow us to see.

When a cataract develops, the lens becomes cloudy and can stop the light rays passing through to the retina and this causes vision to be blurred.

Cataracts usually form slowly and causes a gradual blurring of vision. Often they are diagnosed at routine eye appointments.

Cataracts can also cause glare and difficulty with night-time driving.



Normal vision



Cataracts



Treatment options

- In the vast majority of cases, cataracts are successfully treatable by surgery. The damaged lens is removed and an artificial lens inserted.

Risk factors

- Age
- Heavy alcohol use
- Smoking
- Obesity
- High blood pressure
- Previous eye injuries
- A family history of cataracts
- Too much sun exposure
- Diabetes
- Exposure to radiation from X-rays and cancer treatments

Diabetic Retinopathy

Many diabetics, particularly those with poor diabetic control, have damaged blood vessels in the retina of the eye.

This condition, called diabetic retinopathy, can affect up to eight out of 10 people who have had diabetes for 10 years or more.

There are two main types:

Diabetic Macular Oedema

- Fluid leaks out of the damaged blood vessels and accumulates in the macula causing it to swell and resulting in blurred vision. This can eventually lead to poor central vision.

Proliferative Diabetic Retinopathy

- Blood vessels in the retina become blocked and this means the retina is starved of blood. The body reacts by producing abnormal and fragile blood vessels on the retina, which break and cause bleeding into the eye and scarring of the retina. In some cases, the retina can detach.



Normal vision



Diabetic retinopathy



Treatment options

- Laser treatment to stop further damage but it will not improve sight.
- Stopping smoking.
- Improving blood pressure, cholesterol and diabetic control.

Risk factors

- Duration of diabetes
- Poor control of your blood sugar level
- High blood pressure
- High cholesterol
- Pregnancy
- Tobacco use
- Ethnicity

Hemianopia

This is when you have visual field loss. This means that you are unable to see a section of your field of vision.

This occurs frequently in stroke. The damage to the brain following a stroke can affect the ability of the brain to interpret the information sent to it and it forms an incomplete picture.

It can affect independence as people affected report fear of falling, dropping things and people appearing out of nowhere.

The most common visual processing problem is visual neglect, this means that you are unaware of your surroundings on your affected side.



Hemianopia



Quadrantanopia



Treatment options

- There is no treatment for hemianopia. People affected can be taught scanning techniques and some low vision aids may help.

Risk factors

- Damage to the brain

Charles Bonnet Syndrome

Charles Bonnet Syndrome (CBS) can happen in anyone who has sight loss.

CBS is when someone with sight loss experiences visual hallucinations. When someone has sight loss often the brain tries to fill in the 'gaps' and this results in images appearing.

People who have CBS can experience these hallucinations occasionally, intermittently or constantly.



Facts about CBS

- Approximately one in five people who are vision impaired will suffer from CBS.
- Approximately 80% of those who have a diagnosed vision impairment have not been warned about CBS.
- 50% of those who have a vision impairment experience hallucinations.
- It is caused by hyperactivity in the visual cortex.

Many people who experience these hallucinations are reluctant to tell someone, as they are worried that they have mental health issues.

If you suspect someone is suffering from CBS but has not admitted anything, ask them if they ever see something that is not there.



How do we tell if it is Charles Bonnet and not another issue such as infection, delirium or mental health issues?

Questions to ask someone who is hallucinating:

- How do you feel?
- What does it look like?
- Can you touch it?
- Can you smell it?
- If the hallucination talks to you or smells it isn't CBS
- Make sure there are no other signs of infection/delirium

People may see

- **Simple** – colour blobs, sparks, flashes, geometric patterns, grids.
- **People and faces** – full size or tiny, often dressed in costume, sometimes faceless or in costume e.g. knights in armour.
- **Children** – wandering child or a baby.
- **Animals** – e.g. worms, slugs or snakes. Sometimes seen in food or drink.
- **Text and musical notes** – forming nonsensical tunes or sentences.
- **Buildings and furniture** – including doors, walls, furniture, plants, flowers, trees.

Treatment options

- Ensure the person has been made aware that they may experience hallucinations.
- Important to stress that hallucinations can be a normal response to visual loss.
- Emotional support – reassurance and acknowledgment of what they are experiencing.
- When the hallucinations begin
 - Check physical health.
 - Review medication and side effects.
 - Check for memory problems.

- Tips to stop the hallucinations
 - Reach out and touch – it may disappear.
 - Side to side eye movements in 15 second bursts to interfere with the visual field.
 - Stare at it.
 - Make a change – stand up/sit down/ move around.
 - Holding your breath is one option but you have to do this for a prolonged period so a bit dangerous!
 - Stress can exacerbate hallucinations – consider stress management support.
 - Meditation works for some people.
- Medication Options
 - Anti-epilepsy drugs can work to reduce the hyper-excitability in the brain.
 - Dementia drugs can reduce hyper-excitability.

About Royal Blind

Royal Blind is Scotland's largest vision impairment organisation.

We care for, educate and employ blind and partially sighted people across Scotland.

As part of our services for older people, we run the only care homes in Scotland that specialise in caring for people with a vision impairment, Braeside House in Edinburgh and Jenny's Well in Paisley.

Find out more about Royal Blind at www.royalblind.org

Information in this booklet was sourced from residents and staff of Braeside House and Jenny's Well, Royal Blind, Macular Society, Moorfields Eye Hospital NHS Trust, Christie's NHS Trust, Esme's Umbrella, NHS Choices, RNIB.

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