



Seeing it from their side

A guide to recognising and supporting
sight loss in your care home

RNIB

supporting blind and
partially sighted people

Why do I need to understand about sight loss?

Right now, almost two million people in the UK are living with sight loss. Although it can affect anyone at any time, losing our sight becomes increasingly likely as we get older.

Currently, sight loss affects:

- 1 in 5 people over 75 and
- 1 in 2 people over 90.

People with a learning disability are also far more likely to be blind or partially sighted compared with the general population:

- 18.8 per cent of those with a learning disability are thought to be blind and partially sighted.
- 59.2 per cent have a refractive error. People with a learning disability are significantly more likely to have severe/extreme refractive error, and for this to be uncorrected.
- 42 per cent have been found to have strabismus (a condition in which the eyes are not properly aligned with each other). This is much higher than in the general population (4 per cent).

This means that if you work with older people or those with a learning disability, a significant proportion of your residents – maybe more than half in elderly care – will have a degree of sight loss that can have a serious effect on the quality of their lives.

Because of this, we think it's useful for you to understand:

- the main causes of sight loss
- how these conditions may affect your residents
- what you can do to make sure that you are providing appropriate and safe support to ensure that you comply with the essential standards of safety and quality.

At RNIB, we know you do everything you can to make the lives of your residents safe and happy. We provide residential care for people with sight loss, and we've also produced this brief guide to help you

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make the small changes that can make a big difference for people in your care who suffer from sight problems.

And it's not only your residents who'll benefit. Helping your staff understand the needs of people with sight loss will make their day-to-day caring easier and more effective.

Adapting your service to cater for the needs of residents with sight loss will help you create an even happier, safer environment, and enhance your home's reputation. It'll also help you meet many of the Care Quality Commission's outcomes – and contribute to you passing your inspection.



So who's affected?

Sight loss isn't confined to those who are registered blind and partially sighted. It includes people who are waiting for, or having, treatment such as laser or other surgery to improve their sight. And it includes people whose vision loss could be improved by wearing the right glasses.

These people are living with significant sight loss, and some have vision which is equivalent to people who are partially sighted or blind. Although more likely to experience sight loss, people with a learning disability are much less likely to access eye care so it is likely to be undetected. There is a direct correlation between known learning disability syndrome/condition and associated vision problems.

How can this guide help?

This care home guide is designed to help providers of health and adult social care like you to comply with the Health and Social Care Act 2008 (Regulated Activities) Regulations 2009 and the Care Quality Commission (Registration) Regulations 2009, in particular Regulation 9 of the Act which states:

- (1) the registered person must take proper steps to ensure that each service user is protected against the risks of receiving care or treatment that is inappropriate or unsafe by means of:
 - (a) the carrying out and assessment of the needs of the service user and
 - (b) the planning and delivery of care and, where appropriate, treatment in such a way as to –
 - (i) meet the service users individual needs,
 - (ii) ensure the welfare and safety of the service user,
 - (iii) reflect, where appropriate, published research evidence and guidance issued by the appropriate professional and expert bodies as to good practice in relation to such care and treatment and
 - (iv) avoid unlawful discrimination including, where applicable, by providing for the making of reasonable adjustments in service provision to meet the service users individual needs...

What causes sight loss?

Five common causes of sight loss are:

- age-related macular degeneration
- diabetic retinopathy
- glaucoma
- cataract
- refractive error.

To help you and your staff understand these conditions and how they may affect your residents, there's a brief description of each one on the following pages, along with photographs to show you how the world may look to them. There's also lots more detailed information available at rnib.org.uk.

It's possible to have more than one condition, and for it to be more or less severe than shown. Getting older is one of the biggest risk factors for developing eye conditions which cause sight loss.

Age related-macular degeneration

Also known as ARMD and AMD. It can lead to loss of central vision while side vision remains, and is the most common cause of sight loss in the UK.

AMD occurs when the delicate cells of the macula (a small area at the very centre of the retina) become damaged and stop working. Wet AMD, which can develop very quickly, can sometimes respond to treatment if it's caught in the very early stages. Dry AMD, which develops slowly and causes gradual loss of central vision, can't be medically treated.

Loss of central vision may make reading ordinary print, watching television or recognising faces difficult.

Paul's story

Paul is 30 and has Down's Syndrome. Although he had no previous history of sight loss, his carers were concerned when they noticed he was becoming reluctant to leave his flat and no longer seemed to recognise them. They contacted the RNIB Bridge to Vision Service, who assessed his vision. He was then referred to a local optometrist, who diagnosed dense cataracts in both Paul's eyes.

The RNIB worker helped Paul understand what would happen before, during and after his operation and arranged for him and his carers to visit the hospital to get

to know the staff and surroundings before his admission.

The operation was successful, and Paul now greets his carers, friends and family with a smile of recognition. He can now walk independently from his flat to the front door, and enjoy watching TV, even using the remote control. His carers have told us that support from the RNIB Bridge to Vision Service has been invaluable in helping Paul, and themselves, to understand his visual problems and has made a real difference to his quality of life.



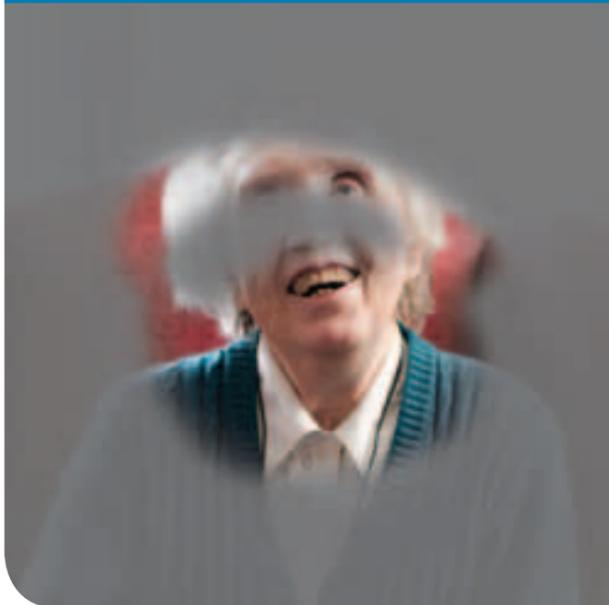


Age-related macular degeneration

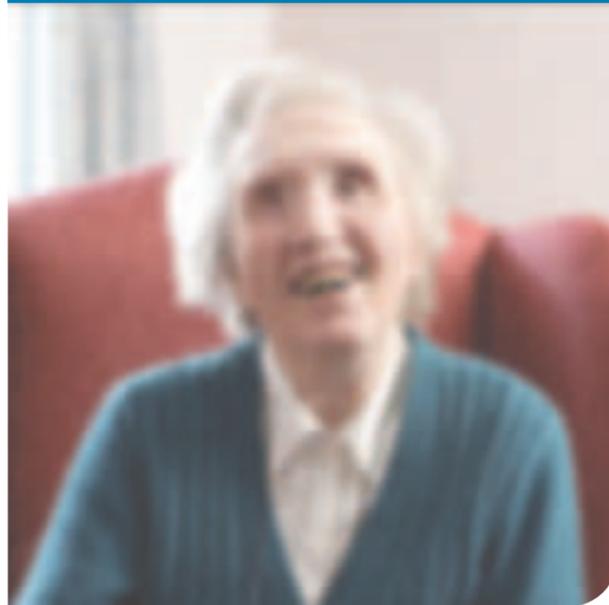


Diabetic retinopathy

Glaucoma



Cataract



Examples of how eye conditions may affect sight.

Diabetic retinopathy

Diabetes can affect the eye in several ways. The most serious affects of diabetes on the eye are the changes it causes to the retinal blood vessels, known as diabetic retinopathy. This happens when diabetes causes the blood vessels in the eye to bulge, leak fluid and blood. This can have a serious affect on vision if left untreated.

Most people with diabetes should have a yearly examination of their retina to check if there are any changes to their blood vessels. This is important because there is a stage of diabetic retinopathy when laser treatment can be used to avoid serious sight loss. Without any treatment diabetic retinopathy can cause very serious loss of vision, affecting both central and side vision.

As well as the yearly examination of their retina, good control of blood sugar (glucose) levels has been shown to help to lower the risk of diabetic retinopathy developing.

Glaucoma

This covers a group of conditions in which the optic nerve is damaged at the point where it leaves the eye. This can result in tunnel vision, and may not be noticed until considerable damage to the person's side vision has been done.

In some people the damage is caused by raised eye pressure, which can occur when the aqueous fluid doesn't drain away properly. It can also be caused because of a weakness in the optic nerve.

Glaucoma can be medically treated through the use of eye drops, drugs, laser treatment or operations, although any damage already caused by the condition can't be repaired.

Cataract

Cataract is a very common eye condition that affects many people over sixty. The symptoms include blurry or cloudy sight, being dazzled by light and fading colour vision. A cataract is a clouding of the lens. Vision becomes blurred because the cataract makes the usually clear lens cloudy, interfering with sight.

It isn't a layer of skin that grows over the eye as is sometimes thought. Cataract can be surgically treated by removing the cloudy lens and replacing it with a clear plastic lens called an intraocular lens implant.

Refractive Error

Refractive errors are problems like short sightedness (myopia), long sightedness (hypermetropia) and presbyopia (need for reading glasses) which can be corrected using spectacles or contact lens. This often goes undetected. Some people with a learning disability may find it difficult to communicate that they have any difficulty with seeing and are reliant on carers to recognise and identify potential vision problems.

Other causes of sight loss:

Stroke

Visual problems after a stroke are common. Strokes can affect sight and vision in a number of ways. The most common effect is called hemianopia. This occurs when the stroke causes damage to the visual parts of the brain. Hemianopia causes a loss of sight in one side of the visual field, which means someone would lose all the right or left side of their vision in both eyes. Unfortunately there isn't a treatment for this kind of problem, although some people may see a slight improvement over time.

Some people with stroke also have problems with visual perception and neglecting to take notice of parts of their vision (visual neglect).

Posterior cortical atrophy

PCA (Benson's syndrome) is a progressive condition where the brain can't process and interpret information received by the healthy eyes. The underlying cause is often Alzheimer's disease.

Susan's story

Before Susan came to RNIB Tate House, she hadn't been managing well due to her sight loss and depended on carers for everything.

Susan lives in an upstairs flat, and, after nine months of orientation training and building her confidence in managing alone, can now make her way around the home using hand rails and vantage points. Susan's first trip to the dining room on her own raised cheers all round. This confidence has motivated Susan to want to do more and she's very proud of her new-found independence.

Although Susan had become isolated where she was, with no outside activities, she now attends the blind society in Harrogate and has arranged further activities outside the home.

The facilities for people with sight loss at RNIB Tate House have enabled Susan to gain the self-esteem and confidence to look forward and plan, and no longer have to struggle in an environment that was unsatisfactory for her. Now that her needs are met, Susan's parents feel secure in the fact their daughter is "settled and happy at last."



How can I identify sight loss in my residents?

There are a number of ways that you can tell if a resident is experiencing sight loss. For example, does the person find it difficult to:

- recognise people?
- be in bright light, low light or both?
- read facial expressions?
- find things?
- read or enjoy hobbies?
- manage unfamiliar surroundings?
- locate food on a plate?
- use their spectacles, perhaps saying, 'I need new glasses'?
- look at something without positioning their head and body in an unusual way?

If two or more of these apply, you need to have the person's vision assessed. RNIB recommends that people aged over 60 have a full eye examination every year. RNIB offers specialist support to enable those with a learning disability to access sight tests.

What can I do to improve things around our care home?

There are many small things you can do around your home for residents with sight problems. For example, you can:

- minimise glare
- increase colour and shade contrasts
- balance light levels
- provide lighting for close work
- reduce the amount of visual information
- provide clear signage in lower case
- keep things in set places
- improve general lighting.

You'll find many more ideas to help your residents in the following pages.



How can I meet the specific needs of our residents?

Making the right assessment

It should be easy to adapt your assessment processes to include sight loss as the areas you need to consider will already be part of your normal processes.

First, no two people with sight loss are the same. You can't assume that two people with diabetic retinopathy will have the same needs, as these will be shaped by all sorts of things, such as other disabilities, personal preferences or cultural background.

Each person's sight loss will be different, and personal to them; some people may not be able to see anything at all while others might have some useful sight. Always make sure you involve the person and ask them what works for them.

Getting their care plan right

There are four areas that you should focus on in your assessment and care plan:

- communication
- the world around them
- dealing with the day-to-day
- moving around.

There's a sample care plan on page 21 to give you some ideas.

Communication – person to person

We all know that good communication skills are essential. But they're even more important when you're working with people with sight loss, who often can't rely on the visual clues that most of us take for granted in our everyday lives. Imagine how you would feel if:

- You were chatting away to a care worker when you suddenly realised that they were no longer there.

- You were sitting in your room when suddenly someone touched your shoulder.
- You were being hoisted when suddenly without warning you were swung into the air.

These types of situations are very frustrating, frightening and confusing for people with sight loss. But you can easily avoid them by:

- Introduce yourself when you approach a person with sight loss, using touch (if appropriate) to let the person know you are there.
- Talk directly to the person and not to their companion or carer.
- Use the person's name when you begin a conversation so that they know you are talking to them.
- Consider your position – a person with AMD for example may prefer you to stand or sit at the side of them because they may have some useful side vision.
- Remember that many people with sight loss won't pick up on non-verbal communication. For example, they won't be able to see you smiling and so might not know you're making a joke.
- Tell them everything you're going to do before you do it and as you are doing it.
- Think about the language and tone you use – 'over there' doesn't mean anything to a person with sight loss.
- Talk naturally. You don't have to avoid words or phrases like 'I see' or 'I was watching television'.
- Tell a person with sight loss when you are moving away from them or leaving the room.

Communication – getting the message across

Written communication can often be difficult for people who don't have enough useful vision to read standard print. Quite often the solution seems to be to read everything out to the person, but this can be embarrassing and frustrating. Imagine how the following would make you feel.

- A care worker read a letter to you that contained personal information.
- You had to rely on someone to read a menu to you.
- You couldn't look at your contract of residency to check out a detail without asking for assistance.
- You couldn't read things at your own pace.

Bernie's story

In 1971, while he was still only in his twenties, Bernie was involved in a car crash which left him with head injuries and blind. After spending years in and out of hospitals and totally unsuitable accommodation, Bernie finally came to RNIB Wavertree House in 1994.

"I've never been so happy as I am at Wavertree. I've gained confidence and independence, I go out alone and I can manage my own financial affairs. My new flat here is wonderful and I've made it my own. I do use the kitchen

facilities but mostly I go to the dining room as the food's so good. All the staff know me well and understand my sight loss and how it affects me at times. They're always helpful and I have a good laugh with them. I wouldn't want to be anywhere else, I have everything I need."

It's easy for you to introduce a few simple changes which will make a real difference (and ensure that you comply with the Disability Discrimination Act 1995, which specifies that service providers must not provide a poorer quality of service to people with disabilities).

- Always ask the person what their preferred reading format is – this could be braille, audio CD, large or clear print etc.
- Always try to produce any information in their preferred format – for larger print you could use a black bold marker pen or a computer to enlarge the font size. You could put information onto a Dictaphone.
- Arrange to have braille, large or clear print and audio CD copies of all your general information such as contracts, fire information and welcome packs.
- Always produce general information in large print. This will benefit the majority of your residents – and probably many visitors and staff!
- Think about buying talking notice boards and using them to tell people what the daily activities programme and menu are.
- Provide simple magnifiers.
- Ensure people can be referred to a low vision clinic (speak to your local GP or social services about this).

The world around them

The home environment can be a difficult place for people with sight loss. Imagine how the following would make you feel.

- You always had to ask for assistance to find things.
- You fell over because someone moved a piece of furniture.
- You couldn't see the edge of your bed because the cover was the same colour as the carpet.

However, people with sight loss don't have to have everything done for them and many would prefer to do things around their home independently. You can make a real difference by making the following small changes.

- If you're helping someone to unpack or arrange their room, always ask where they'd like things to be and show them where you've put them.
- Never move anything in a person's room without asking, including furniture and all personal items.
- Make things bigger, bolder, brighter – for example, make sure the colour of the duvet contrasts with the flooring.

Moving around

Moving around can be difficult for people with sight loss. It can be tempting to keep them safe by asking them not to move around independently or to leave them in their rooms because staff are worried about assisting them to move around in case of an accident. But this means restricting their freedom of movement – imagine how the following would make you feel.

- You were served all your meals in your room alone because staff did not feel confident guiding you.
- You could never walk around without someone telling you to sit down because it's not safe.
- You were constantly bumping into things because they were always being moved.
- You were being guided along a passage and suddenly fell because you reached a step a care worker hadn't told you about.
- You didn't know where you were being taken.

All these problems are easily avoided. You can help people to move around confidently and independently by following these simple guidelines.

- Don't automatically assume that someone with sight loss can't move around independently.
- When a new resident comes to your home, spend some time showing them how to get from one place to another. Explain the route you are taking in detail and point out any clues along the way that will help the person remember the route, such as different flooring, smells etc.
- Make sure the route plan is in their care plan so that everyone follows the same route when they're showing the person how to move around safely.
- Use tactile signage like large raised numbers on doors that people can touch to help them find their way around.
- Find out if the person needs mobility aids and make sure that they are always on hand.
- Use talking notice boards throughout the building to tell people where they are and how to get to the next point.

Guiding

- If a person needs guiding, always ask them how they would like to be guided – don't assume you know.
- Don't hold the person's arm. Let them hold your arm at the elbow, with your arm by your side.
- While you're walking, keep talking to the person, telling them where you're going and what to be aware of (for example, when you're going up and down steps).
- Always look back when you're going through doorways to make sure the person is in the right position and is not going to hurt themselves.
- If the person wants to sit down, tell them that you're going to put their hand on the back of a chair so that they can feel the back and arms. Then allow them to manoeuvre into the chair independently, offering further verbal guidance if it looks as if they may miss the chair. Don't push or pull people into the chair as this can be very distressing.
- Always record the person's wishes in their care plan.

Dealing with the day-to-day

Every day, we all do things like eating, using the telephone, getting dressed, telling the time and watching television. It's very easy to assume that a person with sight loss can't do these things independently, but this doesn't have to be true. Resist the temptation to do things for

Olive's story

Olive is now in her tenth year at RNIB's Tate House residential home in Harrogate. Despite never having any sight in one eye, and the other deteriorating rapidly, she was apprehensive about losing her independence when she moved into residential care. But Tate House has become like a home from home where she can live an independent life with support from the staff.

Although she's always been passionate about painting, especially wildlife, Olive worried that she would have to give up her favourite hobby due to her sight loss. But with the help of visual aids such as magnifiers, task lighting and specially

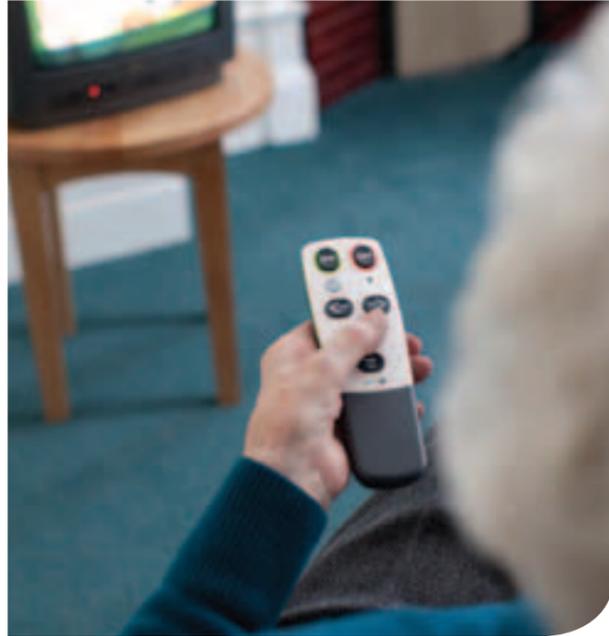
prescribed glasses, and the assistance of one of RNIB Tate House's many volunteers, Olive is able to continue her hobby.

The recent refurbishment of the home has provided better living accommodation and environments for older people with serious sight loss – and given Olive a second hobby. She's taken an active part in the improvements by helping to keep the gardens in good condition and hopes to keep them looking their best in the years to come.

people and work with them to find solutions which enable them to do things for themselves. You can do the following to help people maintain their independence and dignity.

Always ask the person how they want to do something – remember that they may have lived with their sight loss for a long time and will be the 'expert' when it comes to managing it.

- Help people to identify different items – for example by buying different shaped bottles for shampoo and bubble bath.
- Arrange a person's wardrobe colour to help identification, or put outfits on one hanger.
- Think about colour contrast for all items in a person's room – for example a black toilet seat on a white toilet or commode, white guide rails on a dark background, or dark soap and flannels on a white sink.
- Serve food on crockery that contrasts with the tablecloth, for example, white crockery on a dark green tablecloth.
- Consider using plates with rims or plate guards.



- Always set tables in the same way and make sure that you've told people where everything will be.
- Consider using different shaped pots for condiments – say a round salt pot and a square pepper pot.
- Use the clock method when you're serving food and tell people you're using it – meat/fish at 6 o'clock, potatoes/ rice at 12 o'clock and vegetables at 3 and 9 o'clock.
- Always tell people what you're serving them.
- Make sure that all the clocks in communal areas are large and that they're at eye level so that people can see them.

There are many aids available for people with sight loss, such as talking clocks, big button telephones, talking newspapers, audio description for the television, talking microwaves, magnifiers etc, and you can encourage people to use them (see later in this guide for how to order these products).

Writing it down

It's really important to write everything in the care plan so that everyone knows what they should do to ensure that people with sight loss can live their lives independently and with dignity. Opposite is an example of a care plan for an older person in a care home.

For more information on developing care plans or assessments for your residents with sight loss, please contact RNIB (see page 24).

Name Mrs Elizabeth Smith – prefers to be called Betty

Date of Birth 16th June 1928

Eye condition Macular degeneration (central vision loss)

Communication Betty would like people to stand to one side when they talk to her, as she can't see them directly in front of her.

Information Betty needs all information in large print, preferably typed in 16 point font size but can manage with black marker pen on yellow non-glossy paper if necessary.

Environmental factors Betty has a dark green cover on her bed to make sure she can see where the edge is. If this needs changing always replace it with the same colour.

She knows where all her belongings are. They've been placed to enable her to find them easily. They shouldn't be moved without her permission and cleaning staff should be asked to put everything back in the same place.

Moving around Betty is learning to find her way to the toilet. She uses a walking stick, so please make sure she has her stick, walk alongside her and ask her to:

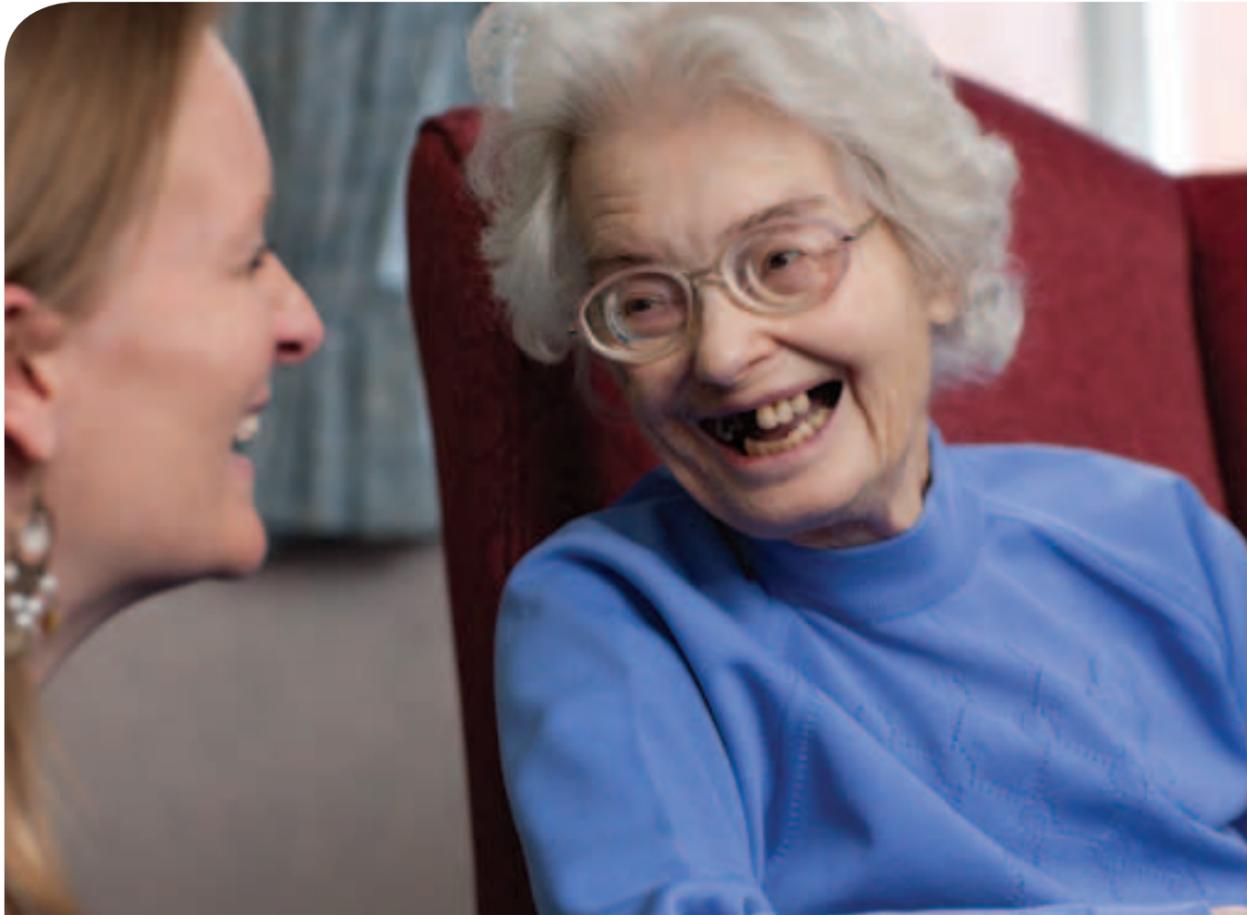
"Walk to the end of the bed. Turn right. Take five steps. Feel furniture. Take 10 steps, feel for the doorframe, which is to your right. Turn right. Walk along the corridor feeling for doorframes. The third doorframe is the toilet." (Betty can feel for the tactile sign on this door.) Reverse this route on the way back to bed.

Everyday tasks Toilet – Betty can use the toilet independently but will need assistance until she has learnt the route.

Bathing/washing – Put a bowl of warm water on the bedside table – flannel to the right of the water and soap dish to the left. Put the towel on the arm of the chair. Betty will sit in the chair and prefers to wash in private. She can use the bathroom independently but will need guiding to and from it. Make sure that she knows where the call bell is before you leave her in the bathroom.

Dressing – Betty's clothes should be placed on the bed next to her chair so that she can reach them.

Eating – Please make sure that Betty's drinks are placed to the left of her dinner plate.



Dementia and sight loss?

Most people with dementia are over 65 and may also be living with sight loss. As the population ages, the number of people with both dementia and sight loss will increase. Studies indicate a higher proportion of residents in care homes may have both conditions.

Most eye conditions that cause sight loss are age-related and some forms of dementia have particular effects on vision. When someone has dementia and sight loss, day-to-day living, mobility, wellbeing and communication are all more difficult than if they only had one of these conditions.

Dementia combined with sight loss can lead to:

- profound disorientation and isolation
- increased risk of falls
- difficulties moving between light and dark
- difficulties learning to use new equipment
- more visual mistakes
- less independence
- misperception and misidentification
- increased worry for carers and relatives.

Visual hallucinations may be associated with dementia or sight loss. They may be distressing for those affected, and may precipitate a move to a care home. More information on visual hallucinations can be found on the RNIB website.

But even in these cases there are practical things you can do to improve people's quality of life and independence, such as using effective lighting and design, which can make the most of their vision and reduce disorientation. Ensuring that the environment makes the most of sight and light, supporting people to wear appropriate spectacles, and spending time getting to know the person all help.

What can RNIB do to help?

We hope that this guide will help you to improve the quality of life for the residents of your home who have sight problems, and help you, and your staff, to look after them. But there's also a whole range of support, advice, products and services that we can provide to help you and your home.

Advice and support

We know that, for many people with sight loss, just being able to carry on doing everyday things like telling the time or reading the daily newspaper can really help their quality of life.

RNIB offers a range of emotional support services to your blind and partially sighted residents, and to those who suffer from other degrees of sight loss. People do not need to be registered blind or partially sighted to get advice or support from us.

The RNIB Helpline offers confidential telephone support, information and counselling to people experiencing emotional difficulties following their sight loss. You can refer your residents to this service or call yourself on **0303 123 9999**

RNIB Visual Impairment and Learning Disability Services provide a range of assessment, support and training to ensure that people with a learning disability have their sight problems recognised and support tailored to take account of sight loss.

Call **0141 772 5588**, email learningdisability@rnib.org.uk or visit [rnib.org.uk/learningdisability](https://www.rnib.org.uk/learningdisability)

Products and publications

Our range includes talking clocks and watches, lighting, magazines, a talking telephone, Big Print newspapers, calendars and diaries to name but a few. We also produce information on making things easier to see and many of the eye conditions that may affect older people.

Contact RNIB's Helpline on **0303 123 9999** to order our product catalogues Everyday Living and Mobility, braille and audio.

You can also browse our full range of books, magazines and products online at [rnib.org.uk/shop](https://www.rnib.org.uk/shop)

Just a few of our products

Clocks and watches: The Communiclock is a radio-controlled talking calendar clock which sets itself from radio signals and announces the day, date, month and year in a natural, friendly voice. There's also the Talking atomic radio controlled watch which has the same features.

Smart Talk Freeview digital box has a seven day talking programme guide, talking reminders and many other special features aimed at allowing blind or partially sighted people to enjoy digital television independently. The box is small, easy to use and can be set up with an existing TV.

Lighting: We provide a wide range of portable lights which are ideal for close-up activities such as reading and crafts. Energy efficient light bulbs, which light up quickly and brightly to make your home safer, are also available.

Games and puzzles: Our range of playing cards come in a variety of sizes and we offer Easi-grip playing cards for anyone who has problems with aches and pains in their hands.

RNIB National Library Service and Talking Books

A subscription to our Library Service or Talking Book Service is a vital part of maintaining a healthy independence for blind and partially sighted adults. We provide books and information in a range of accessible formats, including audio, braille, Moon, large print (16 point font size) and giant print (24 point font size). There is free online access to our reference information, braille sheet music, book lists and a quarterly magazine Read On. We also offer a wide range of magazines and newspapers in accessible formats for readers of all ages (such as large print and audio titles). If you'd like to find out about providing this service to your clients please contact our Customer Services Team on **0303 123 9999**.

RNIB Helpline

0303 123 9999

helpline@rnib.org.uk



Expert support

If you would like to find out more about the information in this guide, please contact:

Debbie Lynch

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Our website

Our website has all the latest information about our work, establishments, services, discussion forums and much more. Please note that none of the RNIB services referred to are restricted to people on the register of blind and partially sighted people; they're available to anyone who's experiencing a sight problem, their family, carers or the professionals who work with them. Please visit **rnib.org.uk**

Our Helpline

Your first point of contact for advice, information and questions. Call **0303 123 9999** or email helpline@rnib.org.uk

Product ordering line

Call this number to order a product, publication or magazine and for information on subscribing to the National Library Service or RNIB's Talking Book Service. Call **0303 123 9999** email cservices@rnib.org.uk or visit rnib.org.uk/shop

Regional contacts

If you have a query regarding working, training or development in your local area, please contact one of our Regional Managers through our Helpline. RNIB's regional work is delivered in partnership with Action for Blind People.

RNIB is the leading charity working in the UK offering practical support, advice and information to anyone with sight loss or those who work with them.