



Understanding Sight Loss

Flexible learning
for staff and volunteers

RNIB People Development

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Introduction

Welcome to RNIB. Our ambition is to make every day better for everyone affected by sight loss – by being there when people need us most, supporting independent living, creating an inclusive society and preventing sight loss.

As a member of staff or volunteer, it's important that you have some knowledge about the experiences of blind and partially sighted people and the impact of losing your sight. This guide is a learning tool which aims to give you an understanding of sight loss, and we ask that you take the time to read it carefully.

How to use this guide

We recommend that you read this guide in sections, with breaks in between as necessary. As you read through this guide, you'll find links to films which you should watch if you have access to a computer or YouTube. You'll also find activities where we ask you to think about a scenario and what your response should be.

For sections 1–7, you'll find a summary of key points for easy reference. When you get to the end of this guide, please take the simple True/False test, which will help you to measure your understanding of what you've read.

If you would prefer the pack in any other format, please contact the People Development team.

Aim of this guide

This guide assumes that you have no knowledge or experience of blind and partially sighted people. It will help you to:

- recognise how our understanding of disability has developed over the years
- begin to develop your understanding of what living with sight loss means
- recognise the etiquette around meeting blind and partially sighted people and guiding
- understand how to work with blind and partially sighted colleagues
- have the confidence to offer help
- understand the responsibilities you have to our customers.

Developing your knowledge and skills further

There is an understanding sight loss course which all staff and volunteers should attend, either in person or by phone, which builds on the knowledge you will gain from this guide.

Depending on your role, there are likely to be additional skills and knowledge you need to develop. For example:

- If you produce documents for either internal or external use, you will need to learn how to make them accessible to people with sight loss.
- If you have direct contact with customers, you may find it helpful to have further training on the emotional impact of sight loss and the use of listening skills.

Whatever your role, we hope you'll keep developing your knowledge and understanding by exchanging ideas with your manager, colleagues and customers. Confident, knowledgeable and skilled staff and volunteers are the greatest asset RNIB has in working towards creating widespread and lasting change.

Section 1:

Supporting independence and inclusion

The last hundred years has been a time of huge social change which helped to create a society where many more people were treated equally.

We've moved from:

- keeping disabled people apart from society, towards integration and inclusion
- assuming that having a disability means being dependent, towards independent living
- building design ignoring the needs of disabled people, to accessibility being a key feature of most new public buildings
- little information being available to people in anything other than print, to a situation where many organisations are now aware of the need to do more – for example bank statements in braille and large print, medical products labelled in braille.

The Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act in Northern Ireland protects people with a disability and prevents discrimination. These discrimination laws protect people from unfair treatment because of their race, age or disability and aim to help create a fair and more equal society.

There is also the UN Convention on the Rights of Disabled People which sets out what States should do to protect and promote the rights of disabled people. This was signed and ratified by the UK in 2009, and the UK has also signed the Optional Protocol which means individuals can complain to the UN Human Rights Commission if they feel a State has breached the Convention. Organisations such as RNIB will use this Convention to hold the government to account as we move forward with its implementation.

Although there have been huge improvements and legislation, people with disabilities are still often discriminated against. For example, only one in four blind and partially sighted people of working age is in employment.



Two models of disability

There are two very different interpretations of the term “disability”.

The medical model

The traditional view is that disability is caused by a physical, mental or sensory impairment. Using this definition, it can be argued that sight loss affects a person’s ability to see and therefore disables them. In response, services and equipment can be offered to help the person with the disability to live independently.

The social model

Another way of interpreting the term disability is to say that it’s not the “impairment” that causes disability, but the barriers that are put up by other people. Being pitied, ignored and patronised are all common experiences for blind and partially sighted people. These attitudes create a huge barrier to independence and the creation of an inclusive society.

Such attitudes go hand-in-hand with other barriers that exclude disabled people from participating in mainstream social life. For example, simple information like a bus timetable that can’t be read makes planning a journey difficult, and employers who are reluctant to employ anyone with any kind of disability places unacceptable barriers in the way of employment opportunities.

This view is called the “social model” and helps focus people’s attention on the social barriers that exist. It puts responsibility on everyone to break down barriers that deny disabled people the same opportunities as non-disabled people.

Using both models

Both the medical model and the social model have their place in helping society to make sense of disability, as disability is a combination of medical and social factors.

For example, a person with sight loss may need a medical approach in the form of:

- emotional support to deal with the loss of sight
- support to develop their skills which will enable them to keep their job or train for a different job.

At the same time the person may also need society to remove barriers such as:

- employers who are sceptical about considering employing a person with sight loss
- inaccessible information
- transport systems that are impossible to use because buses do not announce stops, assistance is difficult to arrange, etc.

It should always be a disabled person’s needs that dictate whether a medical or social approach to their disability is most relevant at any particular time.

RNIB's approach

Both models are needed to explain what we do. We campaign and educate to remove barriers in society, often joining with other organisations to strive for equality for people with sight loss and other disabilities. These activities help us to achieve our strategic goals for two of our priorities:

- Independence – blind and partially sighted people can make the most of their lives
- Inclusion – society includes blind and partially sighted people as equal citizens and consumers.

In a nutshell:

- There are two main ways of understanding the term disability: disability is caused by the impairment (medical model), or society disables people when it doesn't cater for their condition (social model).
- RNIB is committed to equality for people with sight loss and other disabilities and removing barriers in society.

Section 2:

Each person is unique

We use “sight loss” as a universal term, but sight loss doesn’t define a person. Every blind or partially sighted person’s story is different. This is probably the most important learning point to remember as you start working for RNIB.

Some people have congenital eye conditions. In other words, they were born with a sight condition, and may never have experienced full sight or will experience gradual sight loss. Other people develop one or more eye conditions later in life or have accidents that damage their vision. Some people with sight loss have no useful vision, but the majority still have some sight. And for a number of other people, sight loss is just one of a number of disabilities and health problems. As such, the challenges and emotions presented by sight loss are as varied as eye conditions.

Now, we’d like to introduce five people to you, who are blind or partially sighted.

John Thomas:

My name is John Thomas and I’m in my late 70s. I started off as a university teacher and later worked as a radio producer for the BBC. I then moved into consultancy and training in distance education in developing countries, so I spent half the year travelling around Africa and half the year back in the UK.

Throughout my adult life, my sight was diminishing but I still had some sight left until I was about 60. There are a whole range of things that I can’t do for myself since I lost my sight, but it’s not something that I’m acutely conscious of all the time.

[Click here to watch a film about John](#)

Sabeena De Saram:

I'm Sabeena De Saram. I'm 30 years old. I like to be active, and I love rowing. I love my work at RNIB. When I'm not working I make scented candles. I learned how to make scented candles for myself, but now I have started giving them as personalised as gifts for my friends, which I really enjoy doing.

When I was first diagnosed with retinitis pigmentosa, they said it would take at least 20 to 30 years before I lose a significant amount of my sight. But within four years, I had become severely sight impaired.

[Click here to watch a film about Sabeena](#)



Jean Murphy:

I'm Jean Murphy. I'm retired now but my working life was spent being a secretary in all different sorts of jobs which I really enjoyed. I've got two sons, and one little grandson who is the love of my life!

My husband and I have been quite busy and active in the past, but for the last six years, it's been a little bit more difficult because my sight has deteriorated. However we're still quite active – we do a lot of walking and have a good circle of friends. We have an allotment which I can still help with, and this gives me much satisfaction.

[Click here to watch a film about Jean](#)



Lily-Grace Hooper:

My name is Lily-Grace and I'm eight years old. I live at home with my mum and dad and older brother Charlie. I love going to school and my favourite subjects are maths and English. I also enjoy ballet, Brownies and books – my favourite authors are Roald Dahl and David Walliams – and playing the ukulele.

[Click here to watch a film about Lily-Grace](#)

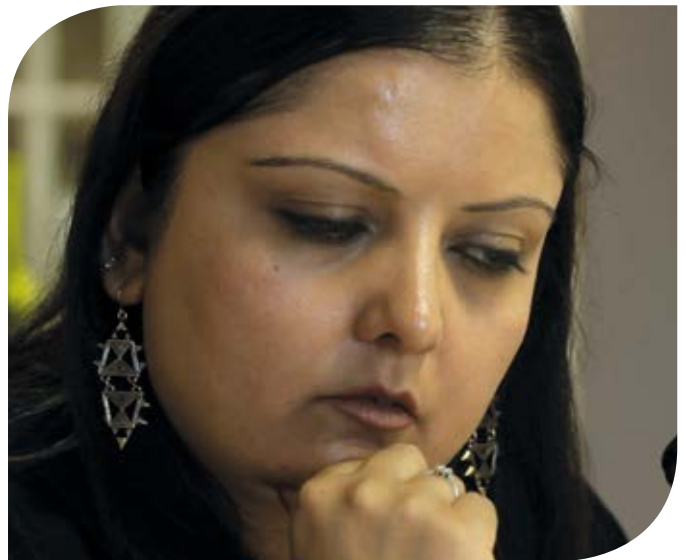


Bhavini Makwana:

I'm Bhavini Makwana. I work full time and I have a family – a caring husband and two daughters, aged 12 and eight. I enjoy going to concerts, pantomimes, the theatre, listening to music, watching TV, going out to eat and swimming.

I was diagnosed with retinitis pigmentosa back in 1997, at the age of 17.

[Click here to watch a film about Bhavini](#)



John, Sabeena, Jean, Lily-Grace and Bhavini are very different people, who just happen to have sight loss. While sight loss has had a major impact on their lives, it doesn't define who they are.

In a nutshell:

Focus on the person first. You can then think about how to meet their needs in relation to their sight condition.

Section 3:

Eye conditions and the language to use

When we talk about people with sight loss, we mean people who have an eye condition which seriously affects their daily lives. More than two million people in the UK are living with sight loss. Of these, about 365,000 people are registered as blind or partially sighted. In this section, we look at the definition of the word “blind”, a few common eye conditions and the language which is the most appropriate to use.

What do we mean by blind?

Many people believe that all blind people have no useful vision. But this isn't true. Many blind people have light perception, meaning they can distinguish between light and dark.

In the UK, ophthalmologists (hospital eye doctors), decide if someone can be registered as severely sight impaired (SSI) or sight impaired (SI). Registration involves consideration of the degree to which a person's central and peripheral vision (also known as side vision) is reduced. For example, regarding central vision, a person can register as:

- severely sight impaired if they can only read the top letter of the eye chart from three metres or less.
- sight impaired if they can only read the top letter of the eye chart from six metres or less.

The terms “severely sight impaired” and “sight impaired” are medical terms and are generally used in the administration of certification. At RNIB, we prefer to use the terms “blind” and “partially sighted”.

People who are registered blind or partially sighted may have some peripheral vision, or they may have central vision but severely reduced peripheral vision. This means that even if someone uses a white cane or a guide dog, they may have some useful vision.

John:

If you're carrying a stick, a lot of people will assume that you're blind. Sighted people often think of sight loss in a sort of binary way – you're either blind or you're not blind, whereas the reality is there it can range from having slight sight problems to barely able to perceive any light at all.

Sight loss affects people of all ages. As we get older we are increasingly likely to experience sight loss. For example, 22 per cent of people aged 75 and over experience sight loss.

Eye conditions

In medical textbooks you'll find hundreds of different types of eye conditions. A few of the most common conditions that you're likely to hear about include:

- age-related macular degeneration
- cataracts
- glaucoma
- diabetic retinopathy
- retinitis pigmentosa
- refractive error.

Each condition is described briefly in the following section.

Age-related macular degeneration (AMD)

AMD occurs when a part of your eye called the macula stops working. If you have AMD, your central vision can become distorted or blurry, and over time a blank patch may appear in the centre of your vision. Your side vision is not affected.

The deterioration of your central vision will make it very difficult to read, write and recognise faces or small objects. But with side vision, it's possible to remain independent. AMD is the most common cause of blindness in older people.

There are two main types of AMD – wet AMD and dry AMD. Treatment is available for the former. They are called “wet” and “dry” because of what happens inside your eye and what the ophthalmologist sees when examining the inside of your eye, not because of how the eye feels or whether you have a watery or dry eye.

Cataracts

A cataract is a clouding of the lens in your eye. If you have cataracts, things will look increasingly cloudy and misty, and lights may dazzle or glare more than they used to.

Cataracts are a common eye condition among older people. However, clear sight can be restored with an operation to replace the cloudy lens with a clear plastic lens. Most cataract surgeries are really successful in providing clear vision.

Glaucoma

Glaucoma is a group of conditions in which the optic nerve is damaged. It is often caused by raised pressure in your eye, when the fluid produced by your eye is too much or can't escape properly through the normal drainage channels.

Glaucoma often goes unnoticed because it's painless. In the early stages, blind spots can begin to form in the outer edges of your vision. Without treatment, your loss of sight will continue to progress so that your field of vision becomes very narrow and it can appear as if you're looking through a tunnel. Glaucoma can be treated with eye drops, laser and surgery, but sight that is already lost can't be restored.

Diabetic retinopathy

Diabetes can affect your eyes in a number of ways, but the most serious eye condition is called diabetic retinopathy. It affects the network of blood vessels in your retina and the condition worsens over time.

At first the blood vessels may bulge or leak blood or fluid, but your sight is not affected. As the condition continues, your macula may be affected and this can cause loss of sight in the centre of your field of vision. Sometimes the blood vessels in your retina become blocked, and in response new but weaker blood vessels grow on the surface of your retina. They bleed easily and this leads to scarring which distorts your retina. Your eyesight can become blurred and patchy, and without treatment, it may continue to deteriorate.



Early laser treatment can preserve existing sight. So if you have diabetes, it's very important for you to have an annual diabetic eye screening as well as regular eye tests.

Retinitis pigmentosa

Retinitis pigmentosa (or RP as it is often called) is a group of diseases that affect the light sensitive cells on the retina at the back of the eye. RP is often inherited and the loss of sight is gradual, usually over a period of many years. People with advanced vision changes because of RP may only be able to see through a small patch in their centre of their field of vision. RP may sometimes lead to serious levels of sight loss and some forms of RP may also be associated with hearing loss.

Refractive error

This term covers a number of eye conditions which can usually be corrected by glasses or contact lenses, for example myopia (short-sightedness) or hypermetropia (long-sightedness). However, some people do not have their refractive error corrected and live with sight loss unnecessarily.

What do you think?

Why do you think that uncorrected refractive error is a major cause of sight loss in the UK?

Being unwilling to have your eyes tested, an acceptance that it's all part of the aging process, concerns about costs, challenges around communication and mobility problems are just some of the potential reasons why people may not have their refractive error corrected.

John:

I have retinitis pigmentosa. It started with night blindness as a child. As an adult, my peripheral vision gradually got narrower and narrower. I had some residual vision until I was about 60, but the last 20 years or so I have been totally blind.

Jean:

Glaucoma was just a word to me and I didn't really know that it was as serious as it could be. I used eye drops, but my sight deteriorated and I lost substantial amounts of my peripheral vision. I had operations to try to stop the pressures rising, by making holes at the back of the eyes and drainage tubes inserted, but none of them seemed to work terribly well.

My glaucoma has begun to settle now, but on the top of that, I have problems with my corneas, as a result of all the operations I've had.

Sabeena:

I was diagnosed with retinitis pigmentosa when I was 26 years old. At that point, my eyes were a bit sensitive to light; other than that I was fine. I could read small print. I lost more of my sight when I was 28. By 30, I had lost the rest of my useful vision, and was certified and registered as blind.

Kristy Hooper (Lily-Grace's mum):

Lily-Grace was born prematurely and had a stroke on day four of her life which caused her to sustain significant damage to her brain and optic nerve. She squints in both eyes and has a condition called nystagmus, which means her eyes are constantly moving.

Bhavini:

I was bumping into lamp posts, bollards and people. I couldn't see in the dark. I was diagnosed with this condition that I'd never heard of before – retinitis pigmentosa – a condition whereby your peripheral vision slowly deteriorates.

In late 2008, my sight deteriorated quite significantly. If the post came, I struggled to read it, if the kids brought paintings or letters from school, I couldn't see them. It became difficult to drop off and pick up the girls, especially in winter when it gets dark earlier. I couldn't let them go to all the after school clubs they wanted to do, and that made me feel guilty. I really miss being able to help them with their homework.

The language of sight loss

As an organisation, we often use term “sight loss” as it’s a concise way to describe the wide range of sight conditions that can affect people, ranging from severe blindness to partial sight loss. However, staff and volunteers should be aware that not everyone we support will recognise or identify with this particular term. For example, someone who was born with no sight will almost certainly not talk about “losing” their sight, and alternatively, someone with an eye condition who was diagnosed and treated early, thus saving their vision, is unlikely to think of themselves as having had sight loss. Nevertheless, these are groups of people, along with many others, to whom we offer support and services.

Sight loss is ultimately a very individual and personal issue and people will refer to their sight condition differently. There are many words in public circulation that could be used to describe sight loss and blind and partially sighted people. But within RNIB, our preferred term is “sight loss”, followed by these alternatives:

- sight or eye conditions
- blind and partially sighted people
- people affected by sight loss
- blind/blindness
- partial sight
- low vision
- people living with little or no sight.

You may also come across the term “visually impaired”, but this is more commonly used by professionals in the health, social care and education sectors (but some blind people may also chose to describe themselves as visually impaired).

Talking to someone about their sight loss

People with sight loss are asked more about the extent of their disability than other groups, very likely because of a general fascination about what it’s like to be blind.

However, before you ask someone about their sight, consider how you would want other people to treat you if you had a disability, or how you would react if someone started to quiz you about a sensitive personal attribute.

This is not to say that blind and partially sighted people are unwilling to talk about their condition or are more sensitive than other people. While there is always a chance that someone might find the topic upsetting, there might be other people who would really welcome the opportunity to share their experiences. It’s more about context – for example, a stranger starting a conversation by asking a blind person “Do you dream in colour?” is likely to provoke irritation. But it would be very different if someone was asking for practical reasons, for example, so they can provide information in the right format, or in the context of a friendly conversation between two people who have more than a passing acquaintance.

You just have to bear in mind that different people will react differently to questions, depending on their levels of comfort and acceptance of their sight condition.

In general, tact is always good, whether you’re talking to someone about their sight or any other personal attribute. However, you should never be afraid to offer assistance if you think someone needs help. In the next section of this guide, we will discuss ways to offer support.

One final important point about discussing sight. Don't be afraid of using phrases such as, "Did you see Coronation Street last night?", "Good to see you" or "See you later". Always use everyday language, as this is what people with sight loss would prefer.

Bhavini:

I don't actually mind being called blind, or if someone says "Oh there's a blind woman there". Because that's exactly what it is. I am vision impaired – I don't mind the words sight impaired, blind, or partially sighted, even though I'm actually registered severely sight impaired.

John:

I think it's important to use language which recognises the range and variety of sight loss, and emphasises the person rather than the condition. So rather than talking about "blind people" or "partially sighted people", I prefer to talk about "people who are blind" or "people who are partially sighted". Thus they are people first, rather than being defined by their sight condition.

I'm not particularly fond of "visually impaired" or "severely visually impaired" – they sound a bit too clinical. If I'm talking about the class of people served by RNIB, I tend to refer to them as "people living with sight loss".

In a nutshell

- If someone is blind, it doesn't always mean they have no sight at all.
- There is a huge range of eye conditions, but some are more common than others. You can find more about them on our website rnib.org.uk/eye-health, or by picking up a leaflet from our Understanding series of eye conditions.
- You should use terms such as sight loss, sight conditions, blind and partially sighted.
- RNIB uses "sight loss" as a concise, universal descriptive term. However, we know that not every blind or partially sighted person will identify with it, as each person's experience is unique.
- It's OK to ask someone about their sight condition if the context is relevant, but it's best to avoid doing so just to satisfy your curiosity.
- Do use normal language; you don't have to avoid using words like "see".

Section 4:

Communication matters

Although we usually do it without thinking, communication is a complex process. Face-to-face communication between people who are fully sighted usually relies partly on visual cues. For example, two friends often won't say their names when greeting each other because each has seen who the other one is.

Therefore, there are occasions when it may be necessary to adjust your method of greeting to allow for the fact that the person you're meeting has limited sight. In this section, we look at some of the basic etiquette around meeting, greeting, guiding and generally being helpful. Much of it is common sense but it's often useful to think about how to behave in advance.

Meeting and greeting

What do you think?

Consider the following two scenarios:

- **Scenario one**
Imagine that you've just entered a building, and a person who you know who is blind is in reception. How would you greet them?
- **Scenario two**
You're in a room talking to a couple of friends. A blind person who you don't know walks into the room. What would you do?

In both situations, you would need to initiate a conversation by speaking.

In scenario one, it's good practice to take the initiative and introduce yourself by name when you meet a blind or partially sighted person, no matter how well you think they know your voice.

In scenario two, even if you've never met the blind person who walks into the room, you still need to take the initiative. Introducing yourself with something like "Hi, I'm Julie, can I help?" or "Hi, it's Julie, are you looking for someone?" can be very helpful.

It may be a good idea to gently touch a person with sight loss on the upper arm so that they know you are talking to them. However, bear in mind that this may not be appropriate on the street as it may

seem threatening or over-familiar.

When you're talking, always talk to the blind or partially sighted person directly, rather than their sighted companion, if they happen to have one. Say the name of the person who you are addressing at the beginning of the conversation so that they know you are speaking to them personally.

Jean:

I would like people to simply ask me if I need any help finding who I am looking for... or generally if I need help. You can feel a bit exposed standing at an entrance doorway, and gentle enquiry would help.

Sabeena :

I would prefer if someone comes to me and introduces themselves. For example, saying "Hi, I work for Transport for London. Do you need assistance?" Something like that, so I know that they're talking to me.

Bhavini:

If someone could let me know who else is in the room, then at least I'm aware when I want to speak to someone. Because the worst thing is coming back home and saying, "Oh who else was there?" and I get told there was a person I've been waiting to speak to for such a long time. So, it's nice when people do name introductions – that helps me a lot.

Describing what's happening

When you're interacting with a blind or partially sighted person, it's often helpful to verbalise your actions. For example, "Here's the coffee. I'll put your cup in front of you, just to the right".

Another example situation is when you're with someone who is blind and you enter a room or building which is either unfamiliar to you both or to the blind person. The blind person may need to know where things like the exits and toilets are and the general layout of the furniture – but just give them the basic details and don't overwhelm them with too much information.

What do you think?

Consider this scenario. Two people are talking, one is blind. David, who is sighted, moves away to talk to someone else, leaving Harry, who is blind, continuing to talk. Harry eventually realises and feels foolish.

What should David have done?

David should have simply made it clear to Harry that he was moving away. The same sort of issue arises when people leave a room without saying they are about to leave. Imagine how frustrating and embarrassing it is to find yourself having a conversation with an empty chair!

Guiding

Common concerns expressed by people new to guiding include:

- Can I offer to be a guide if I haven't been trained?
- When should I offer to guide?
- What if I get it wrong?
- How will I know if someone wants to be guided?

Bhavini:

I like to be guided by someone offering me their arm, which I can hold on to, at the bottom of their elbow. I've had instances where I've been dragged, where they've just grabbed my arm and pulled me. I've also had instances where they'll push me from the back and say "turn right", or "turn this way". That's actually quite scary.

Lily-Grace:

When I don't have my cane with me, I like to be guided by someone holding my wrist. I don't like it when people hold me by the elbow or shoulder because it hurts me. Sometimes people don't ask me if I want help – they just pull me – and I don't like that either. I prefer it if they ask me if I want help.

John:

In terms of how I like to be guided, I like to hold my guide's right elbow lightly with my left hand. This allows me to continue to use my right hand for my long cane. Using this technique means that I'm usually walking about half a pace behind my guide. I also find it very helpful if my guide can offer a brief commentary on the spaces we're passing through – for instance, "door on the right", "steps in a couple of yards, going down", "a chair and the table straight in front of you" (while placing my hand on the back of the chair).

Sabeena:

I am really grateful for help, I really appreciate it. But sometimes, I don't like it when people hold my hand and drag me. I feel a bit intimidated. When that happens, I politely ask them to stop. I say that I would like to hold onto them, rather than them holding my hand and dragging me along with them.

You definitely can offer help if you haven't received training in guiding. If you think someone might welcome your help, then do offer your assistance. Your offer may be accepted or declined. If it is the latter, don't be put off. The next person may really appreciate your help.

If someone accepts your offer to be guided, then you need to ask them how they would like to be guided. Helpful questions include "Would you like to take my arm?" and "Would you like to me to go on your left or right side?"

Grabbing someone's hand or arm is never helpful. Offering your upper arm and then leading are the two key principles of guiding.

Some other basic tips for guiding include:

- introducing yourself, asking the person where they want to go and how they wish to be guided
- matching your pace to the person you are guiding
- giving instructions where necessary but not overdoing it
- being aware of hazards at ground level and at head height
- verbalising your actions.

What do you think?

Here are three scenarios involving Liz, who is blind and is in a situation where she needs someone to guide her.

- **Scenario one**
Liz enters a room and clearly wants to find a chair to sit down. David notices her, but he's not sure how to approach her so he appears to be absorbed in arranging flowers so others won't think he has noticed.
- **Scenario two**
David wants to help Liz to sit in a chair. He takes her arm, manoeuvres her so that the chair is directly behind her and gently pushes her backwards. Liz is quite startled but says thank you anyway.
- **Scenario three**
David notices that Liz wants to sit down. He touches Liz by the arm and asks if she needs help. Liz says 'yes' and takes hold of his arm. David leads Liz towards the chair and then guides her hand to the top of the chair's back, so that she can orient herself and sit down independently.

Which scenario described the most considerate way of guiding Liz? And in scenario one, what should David have done instead?

In your early days of meeting people with sight loss, you may find yourself unsure of what to do or say. If so, please ask them what they would find most helpful or how they would like something done differently. Most people will be only too pleased to tell you. However, if they are not polite or pleased to be asked – don't be put off. The next person probably will be.

In a nutshell

- Always introduce yourself by saying your name when you meet someone who is blind.
- Always talk to the person directly. Never their cane, dog or support worker.
- When you're about to leave a conversation or a room, don't forget to say so.
- It's OK to gently touch a person with sight loss on the arm or say their name so that they know you are talking to them.
- It's helpful to verbalise your actions and describe unfamiliar surroundings.
- Don't be afraid to offer help even if you haven't been trained in guiding.
- Always ask the person how they would like to be guided, don't just grab their arm.

Section 5:

Working with blind and partially sighted colleagues

In previous sections, we've talked broadly about how to communicate with blind and partially sighted people. We'll now talk specifically about etiquette in the professional workplace. At RNIB, you'll be communicating regularly with blind and partially sighted colleagues in a variety of situations. To help you do this in the best possible way, here are some points to consider.

Meetings and group situations

Before a meeting, you should ask blind and partially sighted colleagues how they prefer to receive meeting papers. Some colleagues don't have a written medium they can access away from a computer. This might affect how they read agendas, minutes or presentations. It's often helpful to send these out beforehand if you plan to make them available on the day to everyone else. You can find out more about the different ways in which blind and partially sighted people read in the next section of this guide.

If you're chairing the meeting, always start by asking everybody to introduce themselves and their relative location around the table, for example, "Let's start with Emily, who is sitting on my left." Emily would then say, "Hello, I'm Emily Smith, I work in Fundraising." The person on the left of Emily would then introduce themselves and so forth.

During the meeting, you should always make it clear who you are and to whom you're addressing your comment. Using names is the best way to do this, for example: "It's Rob. So, Janet, do you think we can delay the launch date by a week?"

It can be difficult for blind and partially sighted people to follow who is about to speak or follow eye contact in meetings. This can sometimes lead to them inadvertently interrupting, or failing to find their way into the conversation. It's helpful to say something like "James, I've noted you want to say something, I'll come back to you."

Body language

Sighted people instinctively use body language and visual cues to communicate. Imagine for example, a situation where you're waiting for the lift to arrive. Someone who you don't know, or only know by sight, arrives and joins the wait. You would probably smile or nod at the person as a friendly gesture. In a workplace where there are many blind and partially sighted people, you need to translate visual cues into audio cues. So instead of smiling, a simple "hello" (you don't have to follow this up with a full introduction, unless you want to) will give the person with sight loss an acknowledgement of their presence.

People who have been blind from birth may not instinctively copy or mirror the body language of those around them as sighted people do. So it helps to bear in mind that their lack of, or different body language does not mean they aren't interested or that they're not paying attention to the conversation or discussion.

You may notice many blind people wearing headphones or earphones at work. This is probably because they are using a screen reader (a computer programme that reads out information on the screen). Headphones can lead to the impression that they're cutting off from their surroundings, but this is generally not the case.

You may also find that colleagues who have sight loss will appear more independent in a familiar environment, for example, their regular office or route to work, in contrast to an unfamiliar location. However, they may still appreciate your help in certain situations – don't be afraid to offer assistance if you think they need it. You may find that a colleague declines the offer of being guided one day and accepts it another, depending on levels of light and background noise.

Exhibitions, conferences and networking events

Busy events can be particularly difficult and disorienting, especially in unfamiliar locations. Do be proactive and offer assistance to blind and partially sighted colleagues in such situations – they will appreciate it.

Blind and partially sighted people rely on their hearing to a much greater degree at busy events – and environments where there are lots of echoing noises (in a large hall with wooden floors, for example) can make it difficult for them to hear properly and orient themselves. This is something to consider if you're in charge of booking a venue.

Workspaces

You can help your colleagues to navigate their workspace and stay safe with these tips:

- Always return things to their rightful place so that blind and partially sighted colleagues can easily find them. You should also always ask them before borrowing or rearranging things on their desks.
- If you put something in front of someone who is blind or partially sighted, let them know, for example "Here's the USB stick. I'll just put it down on the desk next to your right hand."
- Never leave cabinet doors or drawers open, as people can walk into them and injure themselves.
- Bags or other objects on the floor can be a trip hazard; try to keep them out of walkways. Sometimes a blind or partially sighted colleague may inadvertently leave trip hazards for others, or their guide dog could be lying down in a position where it could trip people up – do intervene by telling them if you see this.

- Never leave an obstacle unattended, for example a trolley with deliveries or a ladder. If you need to leave a potential obstacle unattended, you should alert everyone to the hazard by attaching an obstacle warning device which beeps – you can ask Site Services for more information about this.
- If you spill liquid on the floor, wipe it up straight away.

Remembering these points will help everyone work together in the best and most considerate way.

Bhavini:

It's nice at work. When someone enters the office, they'll say "Hi Bhavini, it's so and so". So from the get-go, I know who's in the office. At group meetings, I'm made to feel part of the team and not treated differently just because I've got sight loss. If there's a printed document, I'll be sent an electronic copy first. If that's not possible, someone will kindly read the document for me, so I'm not left out.

John:

At meetings, it's useful if people round the table can identify themselves. This gives the blind or partially sighted person a sense of where everyone is seated. It's also useful if the person chairing the meeting calls upon speakers by name so that the person with sight loss knows who's speaking, and also keeps an eye out for when a person with sight loss wants to speak.

In a nutshell

- Prepare for meetings by giving out meeting papers in advance to colleagues who need them in other formats.
- During meetings, always say your name before you start speaking, and if you're directing your remark to a particular person, let them know by saying their name.
- Be proactive and offer assistance to colleagues with sight loss at busy, noisy events.
- Use audio instead of visual cues to communicate.
- Don't assume that someone who is blind is not interested in what you're saying just because their body language is different.
- If you put something down in front of someone who has sight loss, don't assume they'll know. Tell the person what and where the object is.
- Help keep the environment consistent and safe by keeping things in the right place and not leaving obstacles about.

Section 6:

Sight loss and independence

In this section, we explore what helps someone who is blind or partially sighted to live independently.

Getting around

The skills that blind and partially sighted people use to get about indoors and out usually involve making use of what vision they do have, using a cane or having a guide dog. Quite often, these skills are used in tandem with a range of subtler techniques, such as echo location, remembering smells, and noting different floor textures and landmarks. For many people with sight loss, getting around independently isn't a problem as long as the environment is right.

Helpful street features include:

- tactile paving, which can alert someone who is blind to a crossing
- pelican crossings with bleeps, or rotating cones which can be felt by hand to know when it's safe to cross.

However, there are many obstacles which can make it difficult for blind and partially sighted people to get out and about, such as:

- street clutter – for example advertising boards, bollards, bins and cars parked on pavements
- poorly designed street crossings and “shared space” schemes.

Putting thought into the design of the environment supports people who have sight loss to be independent.



Bhavini:

I usually walk to the train station using my long white cane. I know the route, but it's unpredictable every single time, because of all the clutter out there – the bins and bin bags, and the A-boards that keep moving on a daily basis. It can put a real downer on your journey, especially as I can't rush anywhere. I have to leave extra early to avoid these obstacles.

People blocking the pavement by parking their cars on it – I think that's my biggest bugbear. I wish people would consider how really dangerous it can be, because that means I'm forced to go on the road. I wish the streets could be made clutter-free, not just for people with sight loss, but also for people in wheelchairs or people with pushchairs.

Making the most of your sight

People with sight loss can stay independent by making the most of their vision. Doing so revolves around making things:

- 1. Bigger:** Making things bigger makes them easier to see. The object can be designed with this aim in mind – an example is a large button telephone or large print book. Alternatively you can use tools such as a magnifying glass or electronic aid.
- 2. Bolder:** Using colour and tone contrast can make the object more visible – examples include highlighting the edges of steps with colour, putting markings on glass doors, using dark text on a light background or vice versa.

- 3. Brighter:** Making things brighter through good lighting can help enormously. Simple things such as using brighter light bulbs or a task lamp can make a big difference, or having adjustable blinds, illuminated mirrors, and lights over a kitchen bench.

Strategies and gadgets

Blind and partially sighted people have a number of strategies and tools to enable them to be independent. Keeping everything in its place, staying organised, and being inventive and flexible are just some of the strategies which can be employed by people with sight loss to get to the same end result as a sighted person.

There is also a huge range of helpful products and gadgets such as talking watches, talking kitchen scales, embossed rulers, and tactile or audio labels. In recent years, smartphones and other new technologies have become increasingly accessible, and apps to help people with sight loss live independently are being developed all the time.

Jean:

I use technology; I have a smartphone, an iPad and Chromebook. I love them! You can zoom in, they will talk back to you and you can enlarge the text. I use Talking Books too, they're terrific and narrated really well.

Bhavini:

I use a Mac computer with VoiceOver. I've inverted the colours, so I see yellow font on a black background, which I'm able to pick up. The computer speaks to me – if I've got emails, it will read them me, and as I'm typing it will read exactly what I'm typing.

I use headphones at work, so I don't disturb everyone else. But when I'm on the go, I've got my phone, with certain apps like RNIB Navigator, to help me find routes. At home, especially if I'm alone, I use other apps like TapTapSee when I need to make out the difference between a frozen packet of peas, mixed veg or sweetcorn. I'll take a picture of it, and within 30 seconds, I'll get a message back telling me what it is.

John:

I've got a colour machine which I can hold against my trousers and it tells what colour trousers or what colour sweater I'm wearing.

How people read

There are three reading methods:

- using your eyes, to read print on paper or on a screen
- using your ears, to listen to an audio recording or electronic speech created through software
- using your hands, to feel a braille print-out, an electronic braille display or a tactile diagram.

Print

Many people with sight loss can still read print on paper or screen, but they need either clear print or large print.

Clear print is an accessible print standard developed by RNIB for use by all organisations. Our policy is for all RNIB clear print documents to be in a font size of 14 point Arial when produced in Word. Large print can range from 16 to 22 point, and giant print ranges from 24 to 32 point. No single size is suitable for everyone.

People with sight loss may also use reading aids such as hand-held magnifiers, closed-circuit televisions (CCTVs) and screen magnification software. This type of software automatically increases the font size when you read a document on a computer screen.

Audio

There are two main ways of reading by listening:

- Through pre-recorded books, magazines and newspapers, read by a human narrator. RNIB is a pioneer in this area with our Talking Books, which along with our Talking Magazines and Newspapers, can be downloaded online from our Overdrive service or delivered on a USB stick or CD. Readers just need a suitable reading device, such as a DAISY player, e-book reader, an MP3 player or computer or smartphone. Audio books are also available through other providers such as Amazon.
- Through synthetic text-to-speech. You can install screen reader software which reads out the information on your computer screen. Options include NVDA (which is free) and JAWS. These days however, many computers, tablets and smartphones are accessible and come with in-built screen readers (an example is VoiceOver on Apple products).



Braille

Braille is based on a system of six raised dots. You may hear the terms “hard copy braille” and “refreshable braille”. Hard copy braille uses paper; refreshable braille is produced by a computer on a display which usually sits in front of the keyboard. The braille display replicates the text highlighted on the screen.

What is accessible information?

Accessible information means that it is produced in ways that can be read by all of the audience. An accessible document should be able to be read in print by those with partial sight, or by a screen reader such as JAWS, and is in a format that can easily be converted into an audio recording or braille.

Your responsibility

If your role involves providing information, then you have a responsibility to develop your skills in producing accessible formats. Speak to your manager about how you can do this.

When you’re sending information out, you should always check what format people prefer (for example clear print, large print, audio or braille). What’s important to remember is that there is no single method which suits all blind or partially sighted people, and sometimes the same person may use different reading methods depending on the situation.

In a nutshell:

- Always ask which format a blind or partially sighted person would prefer when you’re providing information.
- There is information about how to produce accessible information and our house style on iSite (our intranet) – your manager can show you where to find this.

Section 7:

Feelings and attitudes

In this section, we explore how feelings and attitudes about sight loss affect the way people behave.

Feelings around sight loss

People living with little or no sight face multiple challenges. Loss of sight, whether sudden or gradual, is a major life event, and a person experiencing it may go through a range of emotions, which could include anger, fear, frustration, grief and sadness.

As well as dealing with their emotions, they must find ways to adapt to their changing circumstances and deal with the attitudes and behaviours of others, for example their family, employer, health professionals and the general public.

The person will also need to learn how to talk about their sight loss, how to ask for help when necessary and how to respond in different situations.

Sabeena:

I lost my sight all of sudden, it took everyone by surprise and everyone was traumatised, including me. I didn't leave the house for months. I felt like I didn't fit anywhere. All of the friends I had back then were sighted, and I was the only one who is now blind.

Every day I wake up and I forget that I am blind. I tell myself not to think that I am blind, and get on with my day.

John:

There was one part of me that never believed that I was going to go totally blind. When it actually happened, it was as traumatic for me as it might be for someone who had been involved in a car crash and lost their sight that way. The difference was that I had been unconsciously learning skills to cope with it for years and years.

Bhavini:

I was just numb for almost a year. I think I was in denial and in shock – I didn't understand how it happened to me. I didn't know anyone that was registered blind, or had a sight problem.

After a year and a half or so, I got in touch with my local rehabilitation officer, who came to my home and introduced me to all these gadgets and ways of managing. I had always wanted to go to university but was too scared after my diagnosis. I told my rehab office about this, and we found an evening course. I was trained on how to get there, and to get around by myself in the college. A couple of years later, I met a guy, we dated, and we got married.

Jean:

At the beginning, it was a shock. I didn't know how to deal with it, there wasn't glaucoma in the family so I had no preparation for it. The journey was quite tough and there were times I sat in a chair all day and just cried. But you've just got to come to terms with things and I have support – a very good husband and a very good family.

Each person's experience, and the way they respond to it, is different and unique.

Who else is affected by sight loss?

The impact of sight loss is seldom limited to just the individual – the people closest to them may also be affected emotionally. The onset of sight loss can upset the balance in a relationship, perhaps because of a change in roles, or because a relative or partner takes on additional responsibilities. Another example is a parent of an infant or young child who has just been diagnosed with a sight condition – the parent will probably be feeling devastated and worried about their child's future.

Kristy (Lily-Grace's mum):

After the initial diagnosis, I remember coming out of the eye hospital and throwing up in the street – it was such a shock. Looking back, I feel I didn't really enjoy the first two years of Lily-Grace's life as I was grieving. I knew nothing about blindness – it was fear of the unknown that made it so hard.

In your work at RNIB, you may well come into contact with the family members, friends or carers of people with sight loss. If so, just bear in mind that they may be experiencing difficult emotions and have support needs of their own.

How can you be supportive?

If you meet or have contact with people who are struggling with their own sight loss, or that of a close relative, it's important that you:

- show empathy in the way you respond, for example, simply by taking the time to listen
- are clear about the limitations of your role in providing emotional support and know where to refer people on if appropriate (for example the Helpline)
- know how to get support for yourself, as supporting other people can be emotionally draining.

We offer a one-day workshop which looks at emotional support skills. It is helpful for anyone who has direct contact with our customers. Talk to your manager if you think it may be helpful to you.

Attitudes to sight loss

“It’s not the blindness, but the attitude of the seeing to the blind which is the hardest burden to bear.”

Helen Keller

For most blind or partially sighted people, achieving independence is a primary goal. The attitudes of other people have a major part to play in supporting that independence.

Jean:

My husband found it hard watching me struggle. When I’ve said, “I want to try to cook the meal tonight” he’s learned to let me do it, whereas initially he would want to do everything for me. But that’s not what I want at all. I want to be able to try and to continue to try.

Sabeena:

After I lost my sight, my friends were extra-careful around me and were very protective. For example, when I asked them to take me to Regent Street to see the Christmas lights, they came up with a forced reason why they wouldn’t go. But later, one friend told me it was because they were scared about what might happen to me because it would be dark and busy. But the truth was I could, by that time, take care of myself.

Kristy (Lily-Grace’s mum):

It seems to matter to people what Lily-Grace can and can’t see. They ask, “Well, can she see this?” I struggle to see why it’s relevant. I also have an issue with the fact that they’ll always say it in front of her, like she’s not there. When she was a baby it wasn’t OK, but it was more acceptable; but now she’s coming on nine you find yourself thinking “She can hear you, you know! She is listening!”

Although attitudes to disability have moved on considerably since the days of Helen Keller, there is still some way to go. The classic “Does he take sugar?” syndrome, talking to the stick or guide dog, patronising behaviour, resistance to employing people with sight loss, failure to provide information in a format that can be read, buses that don’t announce stops, family and friends being over protective are just some of the challenges commonly faced by people with sight loss.



Explore your attitudes

As you start to work for RNIB, it is a good time to explore your attitudes and assumptions.

What are attitudes and assumptions?

An attitude is an opinion, feeling or belief that affects the way we behave. Lots of things combine to form people's attitudes, for example how they were brought up, the media, and the influence of the people around them.

We can develop new attitudes if we are prepared to question and challenge our assumptions.

Assumptions are beliefs that we tend to take for granted and rarely question. We all make assumptions – indeed it would be difficult to get anything done if we didn't. However, when faced with new situations, it is a mistake to rely on our usual assumptions. For example, it would be wrong to assume that someone you don't know likes milk in their tea or even likes tea. Instead it would be better to ask the person before pouring a cup.

Sometimes we make false assumptions based on misinformation or lack of knowledge and understanding, and this can lead us to act in unhelpful or inappropriate ways.

What do you think?

Consider this scenario.

Sarah thinks that people who are blind don't watch TV programmes because, she reasons, TV is a visual medium. So she is careful not to discuss TV in front of her new colleague Tom, who is blind.

What might have caused Sarah to make this assumption?

It could have been for a variety of reasons. Simple lack of knowledge may have been the main cause. In fact, over 90 per cent of blind or partially sighted people enjoy TV. Maybe it was to do with the messages Sarah had learned as a child that blind people couldn't do things. Alternatively, Sarah may have met one blind person who didn't watch TV and taken it for granted that this applied to anyone with sight loss. Whatever the reason, Sarah is acting on a false assumption.

Challenge your assumptions and attitudes

Recognising false assumptions is not easy – it means accepting that a belief you hold is not true. It means getting into the habit of asking the question: “What makes me think that?” If the answer is along the lines of, “because that’s what blind people do/ think”, then it’s safer to check the facts.

You can challenge your assumptions and attitudes by being prepared to learn new things – by listening, observing and finding out information. Or you can ask people who are blind or partially sighted what they think and what they prefer. It’s always good to adopt an open mind and remember that everyone is different.

Reflect on what you read in Section 1 about the two models of disability – how might people’s assumptions and attitudes be a factor?

In many ways, society’s attitudes determine the extent to which a person is “disabled”. That is the social model. The more open we are to changing our attitudes, to removing barriers and creating opportunities, the more “enabled” people will be.

By coming together, informing ourselves and changing the way we think about blind and partially sighted people, we can all make every day better for people with sight loss.

In a nutshell:

- Sight loss doesn’t just affect the person with the sight condition; it can also affect their close family and friends.
- Explore your attitudes – why do you have the beliefs that you do?
- Don’t just assume that you’re right. Challenge and question your own views.
- Changing people’s attitudes and assumptions is part of our ambition to make every day better for people with sight loss.

Test your knowledge

You've now reached the end of this guide to understanding sight loss. How much can you remember of what you've read? Take this test to find out, and ask your manager to check your answers.

01.

Disability is a combination of medical and social factors.

TRUE FALSE

02.

Some blind people have useful sight.

TRUE FALSE

03.

AMD is a sight condition that affects your side vision.

TRUE FALSE

04.

Glaucoma may lead to your vision becoming very narrow, as if you're looking through a tunnel.

TRUE FALSE

05.

If you have diabetes, it's very important for you to go for an annual diabetic eye screening as well as regular eye tests.

TRUE FALSE

06.

You shouldn't use normal language, such as "See you later", with blind and partially sighted people.

TRUE FALSE

07.

You need to introduce yourself by name when you meet a blind or partially sighted person, no matter how well you think they know your voice.

TRUE FALSE

08.

When you're interacting with a blind or partially sighted person, you shouldn't bother describing your actions.

TRUE FALSE

09.

You can't offer to guide someone if you haven't been trained.

TRUE FALSE

10.

It's not OK to gently touch a person with sight loss on the arm or say their name so that they know you are talking to them.

TRUE FALSE

11.

It's good to offer your upper arm when you're guiding someone, rather than just grabbing their hand or arm.

TRUE FALSE

12.

You should always say when you're about to leave a conversation or a room where blind and partially sighted people are present.

TRUE FALSE

13.

The best way to guide a blind or partially sighted person to be seated (after asking if they would like help) is to guide their hand to the back of the chair so that they can orient themselves and sit down independently.

TRUE FALSE

14.

It's not important to always close drawers and cabinet doors and return things to their rightful place.

TRUE FALSE

15.

You should circulate meeting papers in advance to colleagues with sight loss.

TRUE FALSE

16.

You can always tell what blind people are thinking by watching their body language.

TRUE FALSE

17.

You should be proactive and offer assistance to colleagues with sight loss at busy, noisy events.

TRUE FALSE

18.

The three ways of making the most of your sight are to make things bigger, bolder and brighter.

TRUE FALSE

19.

You should always ask which format a blind or partially sighted person would prefer when you're providing information.

TRUE FALSE

20.

When faced with new situations, it's OK to rely on your usual assumptions.

TRUE FALSE



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