

# People with sight loss in later life

RNIB Evidence-based review

**RNIB**

Supporting people  
with sight loss

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**Sight loss is closely linked to ageing, and as the number of older people is set to rise dramatically, so will the number of blind and partially sighted people. People in later life face unique challenges as, in addition to sight loss, they are also more likely to have additional health problems such as loss of hearing, reduced physical mobility or dementia.**

**If the right support is available, accessible and timely, older people can manage their sight loss, health and well-being. They can be empowered to lead fuller and more active lives, reducing the reliance on costly health and social care services.**

Vision rehabilitation services and social care are often essential parts of this support, and can contribute to the prevention agenda, but many services have been reduced or are at risk of being cut altogether. It is crucial that society and governments realise the impact of these threats to the quality of life for those in later life with sight loss.

We have worked with blind and partially sighted people to develop this review. It looks in detail at blind and partially sighted people in later life in the UK and includes quotes from people with sight loss to ensure

we hear their voice throughout. Several quotes are taken from new RNIB research called My Voice [1] in which participants remained anonymous. In other cases we have included their name.

This review is aimed at those involved in shaping services and addressing the needs of people with sight loss in later life. It will be of interest to commissioners, those in local government who are planning for the future, Public Health and eye care professionals, voluntary sector organisations writing funding bids, and a wide variety of professionals who work with older people. We look forward to working with colleagues to share learning to promote good practice and to respond to people's individual strengths, interests, wishes and needs, to enable older people with sight loss to live fulfilled lives with the right support.



**I feel that we are sometimes overlooked and maybe our voice is not heard.”**

**My Voice participant, aged 67, living in England**

There are almost  
**2 million**

people in the UK living  
with sight loss

## A note on definitions

In this review we define “older people” as aged 65 and over, unless otherwise stated. We have used 65 as it is the accepted chronological age of an older person among most developed world countries [2]. However, in a few cases we have been limited by alternative definitions used in the source material.

We have also given some statistics relating to people aged over 85 because this is the fastest growing age group in the UK and the incidence of sight loss significantly increases for people aged over 85 [3].

There are almost 2 million people in the UK living with sight loss. This includes the circa 25,000 people annually who are

certified by an ophthalmologist as severely sight impaired or sight impaired and who are added to the registers of around 350,000 blind and partially sighted people maintained by local authorities, as well as those whose sight is just better than the levels which qualify for certification.

It also includes people who are awaiting or having treatment such as eye injections, laser treatment or surgery that may improve their sight. And it includes people whose vision loss could be improved by wearing correctly prescribed glasses. These people are all living with significant sight loss. At least one-third has irreversible sight loss and some have vision that is equivalent to people who are registered as partially sighted or blind.

# Profile of older people

## Population

More than

**10 per cent**

of over 65 year olds have some form of sight loss

**1 in 5**

people aged 75 or over live with sight loss

We are facing a longevity revolution [4]. Today, there are 11.4 million people in the UK aged 65 or over and three million are aged 80 or over [5]. In 2015 there are an estimated 700,000 more people over the age of 65 than there were four years ago [6]. The revolution is set to continue. The number of people in the UK aged 65+ is projected to rise by nearly 50 per cent (48.6 per cent) in the next 20 years (from 2015) to over 17 million [5]. The population aged 85 and above is expected to treble in the next 30 years [5].

Sight loss is linked to age; the older you are the more likely you are to be living with sight loss [7].

There are an estimated 1.6 million people aged 65 and over living with sight loss in the UK. Of these almost 650,000 are aged 85 and over [7; 3]. That's one in five people aged 75 or over, and one in two people aged 90 and over living with sight loss [7; 5].

Of the 342,531 people registered as blind and partially sighted in England, Wales and Scotland, 73 per cent are aged 65 and over [8; 9; 10].

**Figure 1.** Proportion of the general population experiencing sight loss

- Not living with sight loss
- Living with sight loss

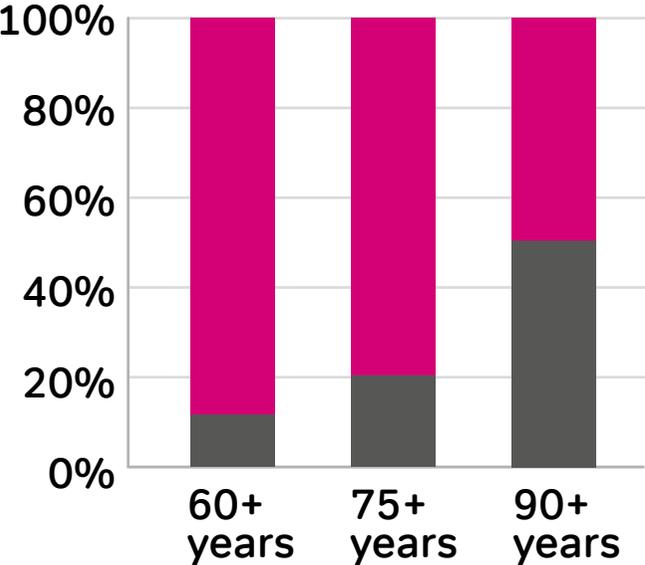


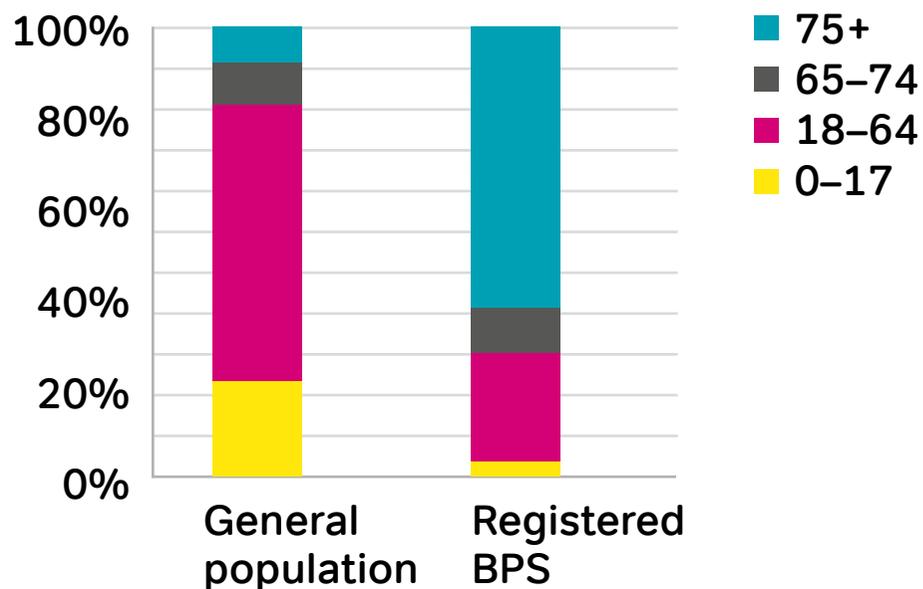
Figure 1 is a bar chart depicting the proportion of people aged 60 years and over, 75 years and over and 90 years and over who are living with sight loss. The chart demonstrates a rising trend from approximately one in nine people living with sight loss aged over 60, one in five people aged over 75 and one in every two people aged over 90 years [7].

Figure 2 shows the difference in age profiles of the general population and the registered blind and partially sighted population.

In the general population 21 per cent are aged 0 to 17 years, 62 per cent are aged 18 to 64, nine per cent are aged 65 to 74 and eight per cent are aged 75 and over.

In the registered population, three per cent are aged 0 to 17 years, 23 per cent are aged 18 to 64, 10 per cent are aged 65 to 74 and 63 per cent are aged 75 and over.

**Figure 2.** Proportion of general population by age



## Major causes of sight loss in later life

The leading causes of sight loss in older people in the UK are uncorrected refractive error, age-related macular degeneration (AMD), cataract, glaucoma and diabetic retinopathy [7].

A high proportion of sight loss in older people is caused by cataract and uncorrected refractive error. For both these causes, with the right treatment and services sight loss can be avoided [7]. Cataract surgery is highly effective and yet there is evidence in England that access to cataract surgery has been unfairly restricted [11]. Refractive error may go uncorrected due to a mistaken belief that poor sight

is inevitable in old age leading to a lack of action to tackle sight loss [12].

The most common eye condition causing sight loss in older people in the UK is age-related macular degeneration (AMD). In addition, over 2 million older people are estimated to be living with the early stages of the disease [7].

It is a mistake to assume that people with sight loss in later life are affected by a single eye condition. A recent survey found that 24 per cent of older people that are registered as blind or partially sighted experience two or more eye conditions [1].



**I think they are not broadcasting enough about Macular disease because it is increasing in hundreds every day. It should be put out there more and let people to know about it.”**

**My Voice participant, aged 80, living in Scotland**

## Sight loss and other conditions



Visual impairment ‘propels’ the disabling effect of other conditions – the double jeopardy of sight loss.”

Dr David Geddes, NHS England, presentation to National Optical Conference, 2015



Over  
**83 per cent**

of older blind and partially sighted people also have additional health problems

Most people over 75 have three or more long term health conditions [13]. New evidence shows that for registered blind and partially sighted people in later life managing multiple health conditions is certainly the norm. Over 83 per cent of registered older blind and partially sighted people also have additional health problems [1].

An estimated 248,000 blind and partially sighted people aged over 70 in the UK also have hearing loss [6; 14].

### Sight loss and dementia

It is estimated that currently about 123,000 people (about 2 per cent of people aged over 75) have concurrent sight loss and dementia. This is likely to be an underestimate as both dementia and sight loss remain under diagnosed [15]. In most cases dementia and sight loss develop independently in older people as they are both common age related conditions. However some forms of dementia cause disturbances in visual function, including hallucinations, and sight loss can also cause hallucinations. The distinction between the causes of hallucinations is not always recognised. Sight loss can make the effect of dementia much more severe, and dementia can make the effect of sight loss much more severe [16; 17].

## Maggie's story

**Maggie is 83 years old and has advanced dementia. She lives at home and is supported by her family, council homecare and a befriender from Alzheimer Scotland.**

At Maggie's last sight test, 10 months ago, the optometrist did not spend much time with Maggie and the glasses dispensed were not suitable. The optometrist also advised that Maggie had "...a degenerative sight loss condition due to dementia..." No further information or advice was given.

Maggie's vision deteriorated. Support staff reported to the family that Maggie was being 'very difficult', would 'lash out'

and was 'aggressive' whenever they approached her. Maggie was referred to RNIB's Vision Support Service for a full visual needs review. The vision support officer used this information to develop a care plan for Maggie and the staff who support her.

A subsequent sight test recorded that in addition to a previously diagnosed cataract, Maggie had extensive age-related macular degeneration and would be eligible for registration as blind or partially sighted. The optometrist advised that Maggie would benefit from having just one pair of single vision glasses for general use, instead of two pairs as previously advised. Maggie's family welcomed this as she became distressed if her glasses were removed.

Maggie's family and support staff were advised about practical

things that could be put in place to maximise Maggie's vision and reduce her stress levels. This included approaching Maggie from her left side (where she had better vision), to approach slowly and to speak on approach to ensure that Maggie was aware that they were there. Previously, approaching on her right side gave Maggie a fright and caused her to wave her arms. This had been interpreted as 'aggressive behaviour'.

Advice on contrast and lighting was also given. For example within the bathroom everything was white and it was noted that Maggie struggled to locate handrails. Orange tape was used to highlight the appropriate rails around the toilet and bath area, and on the floor to mark out a simple contrasting path to the toilet. Previously Maggie would not move within her flat without support. Now Maggie's



family report that she seems to be 'looking' rather than relying solely on the support worker.

Maggie's daughter says her mum now receives the appropriate support and this has helped to reduce her anxieties:

**“... other carers have said that they have more understanding of my mum's disability... [we noticed] a major difference in my mum's care and support from all her carers and family members also... I was given excellent and informative information about my mum's sight impairment and how it wasn't 'just the dementia'.”**

### Sight loss and learning disabilities

It is estimated that there are over one million people in the UK with learning disabilities, including 246,000 aged over 60 [18]. There is a high prevalence of dementia among people with learning disabilities. Dementia was diagnosed in 21.6 per cent, against an expected prevalence of 5.7 per cent, for a group aged 65 and over [19].

### Sight loss and stroke

Stroke affects 150,000 individuals a year in the UK. It's estimated that about 60 per cent of all stroke survivors are left with visual problems after their stroke [20]. A recent survey indicated that less than half of professionals treating stroke survivors referred patients with visual problems to an eye clinic, and a third did not provide visual information leaflets to their patients. This may be

because visual difficulties can be poorly described by patients, particularly where they have communication and cognitive problems [20].

### Sight loss and diabetes

Over 1 in 20 people in the UK have diabetes. All of these people are at risk of sight loss due to damage to their retina (diabetic retinopathy) [21]. Retinopathy frequently has no symptoms until it is advanced so it is crucial for people at risk to undergo regular screening.

Although everyone living with diabetes is offered a free annual retinopathy screening, the take up of this varies considerably between different areas. For example attendance rates in England vary from 66 per cent to 95 per cent, indicating a particular need for this service to be promoted in some areas [22].

Stroke affects

**150,000**

individuals a year  
in the UK

More than

**1 in 20**

people in the UK  
have diabetes



**[I want] the freedom to go out without thinking about whether I may fall over.”**

**My Voice participant, aged 65, living in Wales**

### **Dual sensory loss**

Based on evidence from 2010 [14] Sense estimates that there are now around 250,000 deafblind people in the UK. Most people who are deafblind or have a combined hearing and sight loss are older people who have developed hearing and sight loss in later life. The older someone is, the more likely they are to have both a visual and a hearing impairment. The combination of the two adds up to a serious disability which impacts on their lives and health. People who cannot easily see the television, listen to the radio, read, or take part in activities and conversations can quickly become isolated, leading to boredom, stress, depression and withdrawal.

### **Sight loss and falls**

As falls are the most common cause of hospitalisation for people aged over 65 and the leading cause of death from injury among people aged over 75 [23] preventing falls is a key issue. The cost to the NHS of falls associated with sight loss is at least £25.1 million a year [24] and yet a study showed that only half of falls clinics assessed vision [25]. We estimate that there are over 9,500 serious falls every year that are caused by sight loss and result in hospitalisation [6; 26; 27].

## Sight loss and quality of life



**I would like attending exercise classes... not just exercise, even social gatherings, pottery classes. I would like local councils to be more aware.”**

**My Voice participant, aged 65, living in England**



**Older people with sight loss experience higher levels of depression and anxiety**

## **Sight loss and wellbeing**

Psychological wellbeing is increasingly recognised as a key issue for older people, crucial for overall quality of life and an important influence on physical health [28; 29; 30; 31]. There is a clear link between visual impairment and reduced psychological wellbeing, particularly amongst older people [32; 33]. Older blind and partially sighted people are three times more likely to experience depression than those with good vision [34].

A study showed that over a third of registered blind and partially sighted older people rarely or never felt optimistic about the future. Despite this, only 16 per cent were offered any emotional support in relation to their sight loss [1].



I could have done with some... emotional support, like the fact that I felt completely alone, bearing in mind I wasn't married then and didn't have anybody. I was just left to get on with things."

My Voice participant, aged 67, living in England

### Sight loss and isolation

Older people with sight loss are at greater risk of social isolation than the general population [33]. Some possible reasons for this are described in the My Voice survey [1]. Almost 50 per cent of older registered blind and partially sighted people lived alone; almost 40 per cent never, rarely or only sometimes get as much social contact as they would like and a similar proportion could not make all the journeys they want or need to. Over 70 per cent of older blind and partially sighted people did not use the internet. However, 66 per cent of these people commented that they would use the internet if the barriers preventing them were removed.



I feel utterly lonely... My condition makes light painful to take... I can't go out and meet people."

My Voice participant, aged 73, living in England

Over  
**70 per cent**

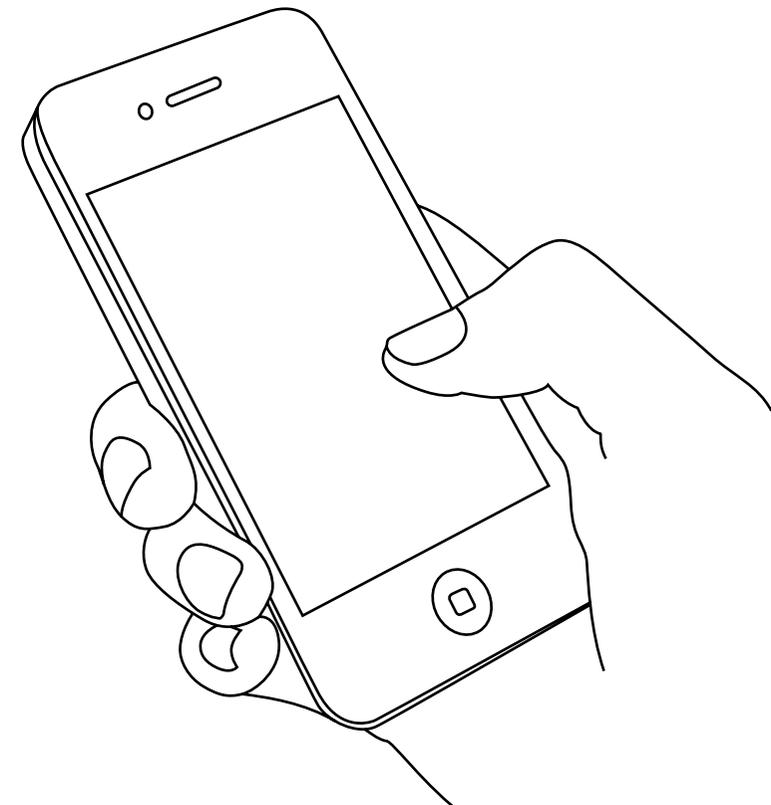
of older registered blind and partially sighted people did not use the internet

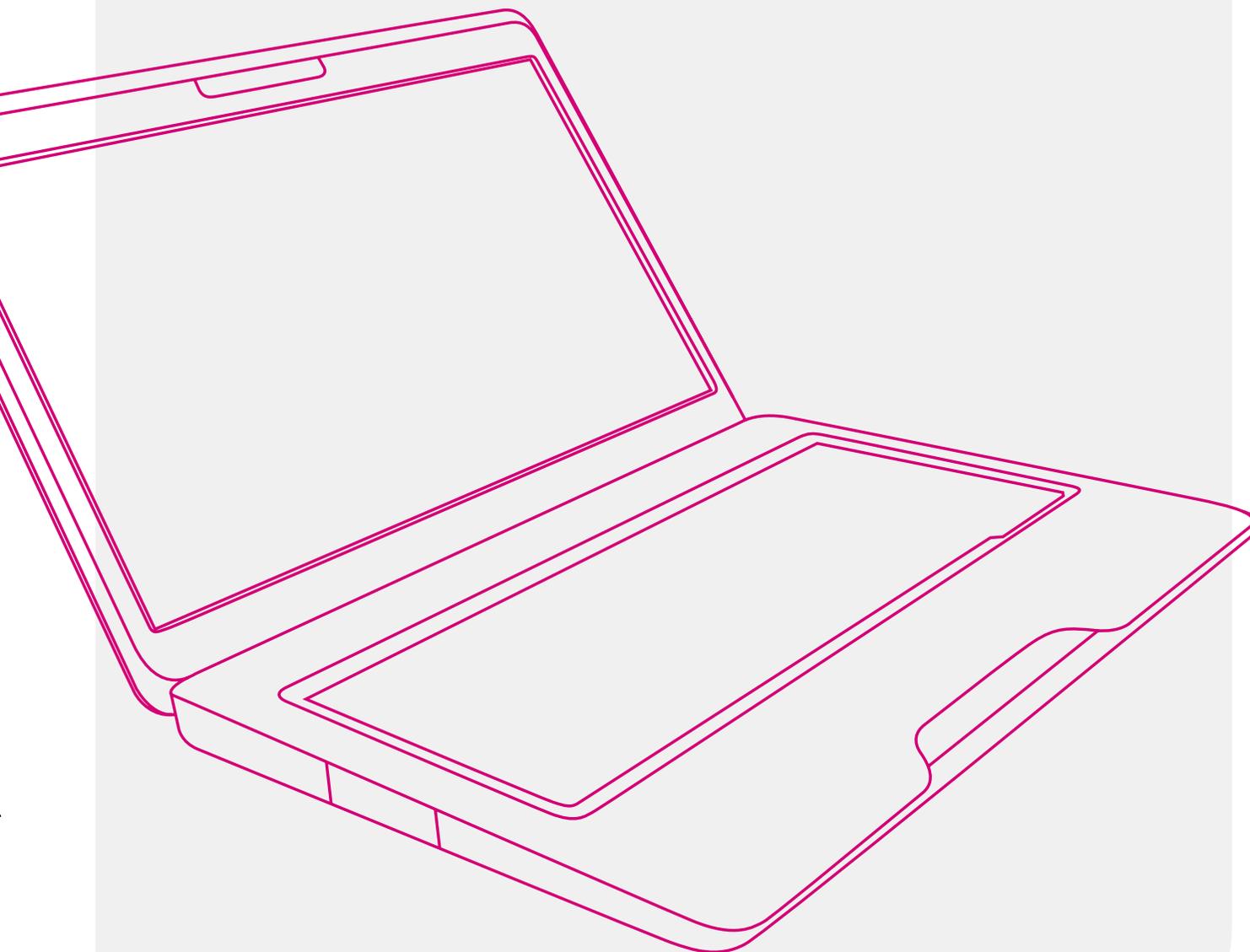
## Roger's story

**Roger is a 75 year old married man who has been blind since birth. He runs his own business researching and developing smart phone technology. He enjoys reading and playing the piano. He recently went abseiling to raise money for charity.**

Roger grew up with two working class parents and two partially sighted brothers and he attended a residential school for blind pupils. After grammar school and university, Roger went on to become a door to door salesman, selling toiletries. He describes this as a formative experience that helped him develop independence.

He has since worked for the Department of Employment, helping blind people into work, and also as a teacher and an Education Advisor. For a short time Roger was a Head Teacher but this did not work out for him. Later in life Roger set up his own business helping disabled people in employment. Nowadays he focuses on smart phone technology that helps blind and partially sighted people travel around.





**“I find technology exciting. I’d like to be young again just to see where it goes next!**

**The internet has been a huge help. Now I can research anything independently. I use free screen reading software on a computer and a smart phone.**

**I’ve always been happy as a blind person. People just need to be themselves and not be afraid to ask for help. We should all aim to be the Chief Executive Officer of our own minds and bodies.”**

## Sight loss and economic exclusion

 I actually didn't realise I could get help so I was forced to sell my house at that time [when first diagnosed].”  
My Voice participant, aged 69, living in England

Sight loss in older people is linked to reduced income, for example sight loss is related to increased likelihood of being without paid employment before pension age [35]. However research published by Demos [36], shows on average an additional £550 spending each month on disability related

expenses such as specialist equipment and taxis, and these figures are an underestimate as they do not take into account indirect disability related costs such as higher electricity bills. Recent research shows that 28 per cent of older registered blind and partially sighted people say that the disability benefits that they receive are “rarely” or “never” enough to meet the extra costs related to living with a disability [1]. In spite of this hardship blind and partially sighted people often do not claim the welfare benefits that they are entitled to: RNIB Cymru and partners’ specialist Welfare Rights Advice Service found that over 60 per cent of the 1,475 cases seen in 2013/14 were under-claiming their benefit entitlement.

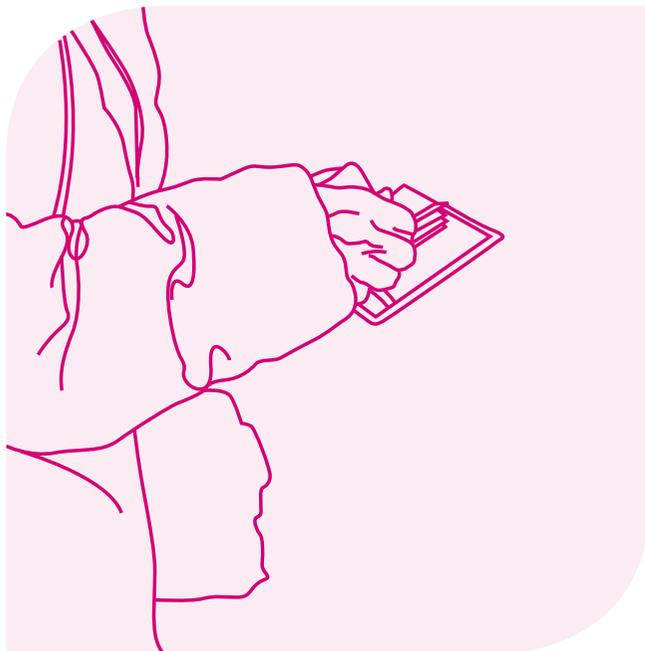


I have difficulty at night with the dark but I can't keep a light on all night. I couldn't afford it.”

My Voice participant, aged 71, living in Wales

An additional  
**£550 per month**

is spent on disability related expenses



## Services and support

### Health

Older people are the biggest users of health services, for example approximately two thirds of NHS patients are aged 65 and over [37]. However, RNIB's My Voice survey showed that over 25 per cent of older registered blind and partially sighted people had some or great difficulty accessing health services [1].

### Eye health and sight loss prevention

In England, for every ten pounds spent on NHS Eye Care services only one pence is spent on prevention. (This does not include NHS sight tests in primary care or cataract surgery and AMD injections in secondary care). This is comparatively low compared to other care settings. For example, six times more is spent on the prevention

of dental problems or hearing problems in comparison to sight problems [38].

Those more at risk of sight loss are people on low incomes, older people, and people from certain black and minority ethnic backgrounds [39]. In addition more people with complex health needs are living longer and will present a different set of challenges for services as they age [18].

Some older people have the mistaken belief that poor sight is inevitable with age [40] despite the fact that many people's sight can be improved through the provision of correct spectacles [7]. In 2013/14, around 10 million over 60s were eligible for a free NHS sight test in England and Wales, yet only 5.9 million NHS sight tests were claimed [41; 42]. Many older people don't see eye

examinations as an essential eye health check and evidence shows that the cost of glasses, transport problems and lack of local access to optometry present barriers to accessing eye tests [39; 43].

People with existing eye conditions are also at risk of further sight loss. Over 78 per cent of older people registered as blind or partially sighted had experienced further deterioration in their vision in the last year [1]. In an effort to reduce preventable sight loss among patients aged 65 or over the Royal College of General Practitioners has chosen Eye health with a focus on ageing and sight loss as one of its clinical priorities until March 2016.

Hospital eye services, under constant and growing pressure, are characterised by long waiting times for outpatient appointments and an over-reliance on eye casualty. From 1 April 2013 the Government began measuring the number of people in England who lose their sight due to three of the main causes of sight loss: glaucoma, age-related macular degeneration and diabetic retinopathy. Reporting on this Public Health Indicator will support the promotion of practices that minimise the sight loss caused by these eye conditions [44]. In Northern Ireland, work has started to implement the recommendations of a new commissioning and provision of eye care services strategy [45].



**Being very short sighted... means thick lenses are needed which are very expensive.”**

**My Voice participant, aged 74, living in Northern Ireland**



**I feel that I need not have suffered the trauma I suffered, after I lost my sight, if I had been offered support and information at the right time.”**

**Padma Cheriyan  
aged 76, living in England**

### **Early intervention**

Sight loss advisers, including Eye Clinic/Care Liaison Officers (ECLOs) and Vision Support Officers (VSOs) work within the eye department and compliment the clinical service provided by ophthalmologists, nurses and other medical staff. They provide emotional and practical support, and are often the first point of contact for the patient in their sight loss journey. A recent RNIB survey of over 600 patients found that 75 per cent of respondents reported that they either agreed or strongly agreed that the ECLO service had a positive impact on their lives [46]. In addition RNIB research carried out in one eye department, estimated that integrating a sight loss adviser service could deliver a financial return to health and social care budgets of £10.57 for every one pound invested [47].

Older people are the largest proportion of people issued with a Certificate of Vision Impairment (CVI) in England and Wales, and the largest proportion registered in Scotland [48], each year. When the certification and registration process works well it can have a positive impact on someone's life and wellbeing. However, delays to the process can be distressing [49; 9].

Sight loss advisers play a key role in ensuring the effective administration of certification (England, Wales and NI) and registration (Scotland). Over 96 per cent of ophthalmologists surveyed by the Royal College of Ophthalmologists believe that sight loss advisers are beneficial to both them and patients in relation to certification [50].

However RNIB data suggests that only 30 per cent of eye departments in the UK currently have access to a qualified sight loss adviser [51]. In addition, many of these posts are currently under threat which jeopardises the quality and consistency of patient care and also negatively impacts patient experience [52].



The clinical staff are very busy but very helpful. There isn't any other staff available... not necessarily social services just someone available to talk to.”

My Voice participant, aged 83, living in Scotland



[I wanted] somebody to sit down with me and my family and talk to me about the loss of my sight and what this would mean to me and my family.”

My Voice participant, age 69, living in Scotland

Only  
**30 per cent**

of UK eye departments currently have access to a qualified sight loss adviser

## Support to help people live independently

It is important to recognise that much sight loss in older people occurs gradually over time. Almost half of older people registered as blind were first registered as partially sighted. This means that many older people have to learn and relearn how to adapt to sight loss as their sight deteriorates [1].



### Vision rehabilitation

Vision rehabilitation, which is often triggered by the registration process, is a key reablement service for older blind and partially sighted people who need to learn a new set of skills. Securing specialist vision rehabilitation support gives people with sight loss confidence, makes them feel safer and helps maintain independence [53]. It also offers cost savings in terms of preventing loss of independence and reliance on other services [54].

While the Care Act 2014 [55] offers a strong framework for local authorities to provide vision rehabilitation and preventative services for blind and partially sighted people in England, specialist vision rehabilitation services are under significant threat [56] and those who need it often wait over six months after making contact to receive a visit from social services [1].

 **[They] could have referred me to RNIB services because I struggled for 12 months without help. It was not necessary. I could have got that help immediately, it would have made a lot of difference.”**

**My Voice participant, aged 69, living in England**



They could have done, at the time, what they did two and a half years later. After the initial assessment I was told the lady would be in touch. When I rang the lady was off sick, then left. Eventually I was re-allocated. The support I've received since has been excellent.”

My Voice participant, aged 82, living in Wales

To find out about RNIB's position on vision rehabilitation, and how the Care Act and associated statutory regulations and guidance relate to blind and partially sighted people please visit [rnib.org.uk/socialcarecampaign](http://rnib.org.uk/socialcarecampaign)

### Social care

Older people are the biggest users of adult social care services. While local authority budget cuts have resulted in a decline within all groups in the numbers of people getting social care, blind and partially sighted people are being disproportionately affected [57].

In England, between 2005 and 2014, over 50 per cent fewer blind and partially sighted

people aged over 65 have received council care and support, despite the fact that the older population has increased considerably during this time. In particular the decline in community based services (such as home care, day care, meals services) is greatest for older blind and partially sighted people [57].

Conversely in Northern Ireland there has been a 35 per cent increase in the number of blind and partially sighted people accessing social services/ community care [58]. This may be due to the embedding of ECLOs into eye departments since 2012 via a national statutory contract.

### Accessing information

Older people with sight loss report difficulty accessing information about services [59; 60]. Almost 90 per cent of registered blind and partially

sighted older people found it difficult or impossible to read information on medication, and 93 per cent found it difficult or impossible to read the information on food packaging [1].

 **Most medication has braille on it and the most frustrating thing is that the staff put labels over the braille.”**

**My Voice participant,  
aged 70, living in Scotland**

As more services are managed online, older people with sight loss who are unable to access services via digital means, will find it increasingly difficult to get appointments with the doctor, arrange visits from social services, or have contact with housing associations. There are national policies to support

older people to get online but as people with sight loss face additional accessibility barriers, they will need additional resources (extra equipment and training) before they are able to use the internet independently. Online Today is a new Big Lottery funded project led by RNIB, delivered in partnership, to help people with sensory loss across the UK to get online.

 **My tablet is very important, more than telephone and even computer.”**

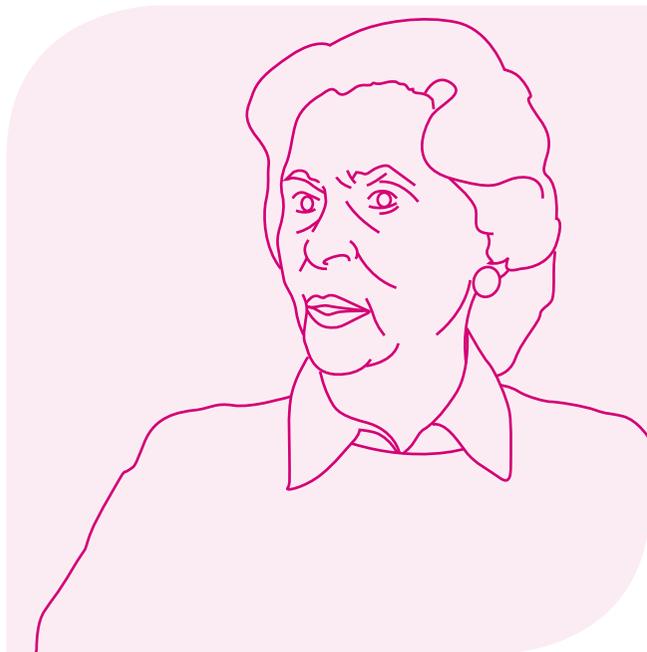
**My Voice participant,  
aged 71, living in England**



**I spend a lot of time online and the internet has become my best friend. I am now 88 and live on my own. I spend my time talking to friends and family, looking at antiques online and viewing houses I'd like to buy! It really brings me enjoyment.”**

**Joyce Weaver-Charles,  
Port Talbot**

## Getting out and about



**I feel very isolated, I live in a very rural area.”**

**My Voice participant, aged 85, living in England**

Travel and getting out can be particularly difficult for older blind and partially sighted people. RNIB found that half of registered older blind and partially sighted people needed support to leave their home and yet local authority cuts pose a risk to access to transport. Over 40 per cent of local authorities in England made cuts to bus services in the financial year 2012–13 [61]. Age UK found that these cuts meant older people struggled to get to hospital and doctors’ appointments, stayed in, missed social activities, and found it hard to keep up voluntary and charitable work [62].



**It would be nice if somebody could ... once a month, take me shopping into town. I’m losing my confidence amongst people, going out on my own that is where I’m losing confidence.”**

**My Voice participant, aged 80, living in Scotland**

## Housing

 I would be happier if I could have my garden done. I can't afford a gardener so I keep the blinds drawn so I don't see it. The council won't do it because I own the house."

My Voice participant,  
aged 84, living in Wales

Older people spend around 90 per cent of their time at home [63] so their housing has a direct impact on their wellbeing and independence. For people with sight loss, and especially those who have acquired sight loss in older age, the type of housing and adaptations they have to meet their needs is of great importance. The Welsh Government sets out design guidance on accessible housing for people with sight loss [64]. Housing associations and councils in Wales are required to meet the associated standards (DQR 2005).

Older people spend  
**90 per cent**

of their time at home

## Dignity in care

Many registered blind and partially sighted people rely on carers, family and friends for support. Some older people with sight loss also act as carers themselves for other family members or friends [1].

There are around 400,000 older people living in care homes in the UK [65] and we know that one in five people aged over 75 and one in every two people aged over 90 years is living with sight loss [7].

 My wife has Alzheimer's disease which makes life difficult."

My Voice participant,  
aged 97, living in Wales

- In 2011 the Equalities and Human Rights Commission undertook an inquiry into home care provision for older people [66]. Evidence showed that people with sight loss were involved in some of the most disturbing examples of poor treatment:

- The report also noted that people with sight loss found it difficult to complain and indeed, were viewed by carers as less likely to complain than those with sight. A lack of knowledge around sight loss can be a further barrier: of the 50 service specifications (the contracts that domiciliary agencies work to) submitted, only 17 mentioned sensory impairment or sight loss.

- Lack of awareness around sight loss can be a problem [40]. Supporting care home residents to look after their eye health is commonly seen as an optional extra, rather than as an integral element of supporting good health and independence [12]. NICE has published guidance stating organisations providing care should ensure that staff are trained to be alert to specific needs arising from sensory impairment in older people in care homes and to record them in a care plan [68].

 I recently had to stop a carer throwing a blanket over a service user's head. She seemed to think it was amusing to humiliate [the] service user, who was visually impaired, but the most concerning thing was that she did not understand what she was doing was wrong.”  
Homecare worker – Private sector [67]

 People are inclined to imagine that you are stupid and can't do something.”  
My Voice participant, aged 66, living in England

## Policy context

The current economic and policy environment offers little to cheer those seeking to improve support for older people with sight loss [4].

### Spending cuts

Cuts to the health budget of £22 billion and reductions in social care spending will all impact directly on older people with sight loss. In addition the resulting reductions in wider public services such as libraries, public transport and leisure services will further disadvantage many older people with sight loss. Welfare reform is also creating additional difficulties and anxieties for people with sight loss.

### Commissioning and capacity

As budgets are cut, health boards, Health and Social Care Trusts and the NHS are attempting to make efficiency

savings by restructuring, introducing new commissioning processes (in England) and reviewing services. Eye health and eye care services not only have to cope with an increasing older population but potentially will be supporting them with treatment for longer. This presents challenges in a time of funding restraint. There is already evidence that areas of the UK are responding differently and there are many examples of inequality of access to sight saving treatments, and emotional and practical support [11]. Lack of capacity is leading to people with treatable eye conditions losing sight unnecessarily because they are not being routinely monitored and treated by the NHS [69].

### Changes to health and social care services

The health and social care landscape has been under unprecedented change over the

last five years and it continues to evolve. Each UK country has embraced health and social care integration at different rates. In Northern Ireland services are already integrated. In Scotland budgets must be ready for integration by 1 April 2016. In England central government is devolving spending decisions for both health and social care to local authorities. These changes may present opportunities for engagement with policy makers at a local level and to raise the issue of sight loss in the local population. It will be important to strengthen referral pathways and recognise the Adult UK sight loss pathway [70] to ensure a smooth and timely transition for people losing their sight from referral and diagnosis, through to early intervention and community support, to enable them to live as independently as possible.

## Learning from the evidence

### Involving older people with sight loss

Policies and services that aim to ensure that everyone has an opportunity to age well must respond to issues of sight loss and support those who live with it to maintain social networks, independence, wellbeing and general health.

### Preventing unnecessary sight loss

Whilst we welcome the Public Health Indicator and the Royal College of General Practitioners' (RCGP) clinical priority as steps forward for older people's eye health, all too often eye conditions go undiagnosed and untreated. This reduces independence and confidence and increases the risk of injury. Identifying sight loss and maintaining eye health should

be seen as a key part of ageing well and supporting older people to live an active healthy life.

### Improving access to health and care services

The role of sight loss advisers is critical in ensuring we use the point of diagnosis to connect with older people with sight loss, offering them information, advice and access to wider health and care services and the agencies that can offer support.

A seamless service with appropriate referrals will include effective vision rehabilitation, which is vital if older people with sight loss are to remain active and independent. To be most effective, this support must be informed by, and co-produced with, older people with sight loss.

Older people with sight loss are a diverse group and access many different services, some

Older people with sight loss often live with

**3 or more**

long term health conditions



specialist, some not. It is important that eye health and sight assessment are high on the agenda for all those working with older people, particularly in relation to dementia, learning disability, diabetes, stroke or conditions where other disabilities may mask the symptoms of sight loss. While some professionals may acquire experience in issues related to sight loss, additional training is not compulsory for most professional groups. It is important that all professionals supporting older people can identify sight loss and support older people to maintain their eye health.

### **Reducing isolation**

Older people with sight loss, particularly those over the age 75, often live with three or more long term health conditions, making it even more of a challenge to maintain

independence, social networks and wellbeing. They face a complex set of barriers to getting out and about and accessing information including difficulty in accessing the written and spoken word, a lack of confidence to ask for assistance, and service providers lacking understanding of their needs. Accessing information becomes increasingly important to older people as they need to make decisions about care needs, claim benefits to which they are entitled, budget effectively and adjust to life with sight loss. However printed and digital information are often not accessible and the increased use of the internet to manage our lives can leave older people with sight loss further disadvantaged.

# What needs to happen now

**We must work together to ensure that those in later life are empowered to make their voice heard.**

**Policy makers and those designing services should**

- engage with older people with sight loss at all stages of the process.

**Commissioners should**

- use the information available to develop accurate health needs assessments which reflect the eye care needs of their local populations, and ensure that service delivery plans include provision for people with sight loss.

**We must work together to ensure that maintaining eye health is a key part of ageing well and support older people to live an active, healthy life.**

**All professionals and agencies working with older people should**

- encourage older people, especially those most at risk of sight loss, to have their free routine eye tests and take responsibility for their own eye health to help reduce avoidable sight loss
- ensure that all those supporting older people receive training about sight loss including as a mandatory part of service induction.

**We must work together to improve access to support at diagnosis and beyond by ensuring that people in later life have the information and advice they need to enable them to manage their own eye health, make informed choices about the support they need and to maintain a good quality of life.**

**Every hospital trust should**

- provide every older person with sight loss access to a sight loss advisor
- provide additional support for older people with complex needs so that they can access services to identify and diagnose sight loss
- implement the NHS information standard so that all patients are provided with personal health information in a format they can access.

**We must work together to design and deliver an integrated service for people in later life. This must be personalised; must address sight loss and functional vision together with other needs and aspirations in a joined-up way; and it must be available and accessible.**

#### **Local councils and health boards should**

- ensure that the devolution plans effectively meet the demands of the Care Act including providing structured vision rehabilitation as a preventative service, not subject to eligibility criteria for care support
- ensure that they have quality assessment processes in place, to understand the unique needs of blind and partially

sighted people and recognise that older people may have care needs beyond vision rehabilitation support

- protect public and community transport services and ensure they are as accessible as possible.

 **I was very lucky to see the rehab worker, and I don't think that would happen now. However in all the years since there has never been any follow up or further support. There is still a lot to do."**

**Padma Cheriyan**

#### **All service providers should**

- work together to provide tailored packages of support which are integrated and respond to the wider economic, social and emotional needs and goals of older people with sight loss
- embed provision of accessible information and promotion of skills for digital inclusion into all services for older people so that those who are blind and partially sighted and those from BME communities are included.

## The eye care sector should work together to

- influence and support commissioners, providers, public health professionals, regulators and care sector organisations to provide effective eye health, eye care and person centred or citizen centred care to older people with sight loss
- provide a UK wide network of peer support so that those in later life with sight loss can maintain social networks, make new friends and share practical tips with one another.

**Older people with sight loss are a growing part of our society with a lot to offer. With the right support at the right time they can age well, make the most of their own life and contribute to others.**



**I wish ... people wouldn't feel sorry for me or sympathise. That makes me very angry. I wish they would see the person first and not the disability."**

**My Voice participant, aged 69, living in England**

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## About our evidence

RNIB is a leading source of information on sight loss and the issues affecting blind and partially sighted people.

## Sight loss data tool

Our Sight loss data tool provides local and regional facts and figures about blind and partially sighted people and those at risk of sight loss.

[rnib.org.uk/datatool](http://rnib.org.uk/datatool)

## Research reports

We carry out and commission a wide range of research on the issues that affect blind and partially sighted people.

[rnib.org.uk/research](http://rnib.org.uk/research)

## Knowledge Exchange Network

The Knowledge Exchange Network for the Sight Loss Sector has been set up to help professionals generating and using research and information on sight loss. To find out what the network can offer, and to receive our email updates visit:

[rnib.org.uk/ken](http://rnib.org.uk/ken)

For research enquiries please email [research@rnib.org.uk](mailto:research@rnib.org.uk)

**RNIB**  
**105 Judd Street**  
**London WC1H 9NE**

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National Helpline 0303 123 9999  
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