



Evidence-based review

Older people

RNIB

supporting blind and
partially sighted people

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Introduction

Blind and partially sighted people come from every section of the community and sight loss affects people of all ages. Each is a unique individual. However there are some common issues and challenges that affect blind and partially sighted people in particular age groups.

Every year RNIB publishes “Sight loss UK”, which reviews the evidence we have about the lives of people living with sight loss.

This review looks in more detail at the experience of older blind and partially sighted people in the UK. It includes a profile of this group, the policies that govern their access to health, social care, and other services, and a commentary on what the evidence tells us.

In this review we define “older people” as 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 [1]. 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 [2].

Profile of older people

Population

- The UK population is ageing, with the number of people over the age of 85 increasing the most. In 2010 there were 1.7 million more people over the age of 65 in the UK than 25 years before [2].
- Sight loss is linked to age; the older you are the more likely you are to be living with sight loss [3].
- Around 1 in 7 people over the age of 65 and 1 in 3 people over the age of 85 in the UK are living with sight loss [3].
- An estimated 1,430,000 people aged 65–84, and 580,000 aged 85 and over are living with sight loss in the UK [4].

Causes and prevention of sight loss in older people

- 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 [3].

- Over 500,000 older people are living with late stage AMD in the UK. In addition, approximately 1.8 million older people are living with the early stages of the disease [5].
- Over 300,000 older people are living with glaucoma, either detected or undetected [6].
- Around 570,000 people aged 60 and over are living with a cataract in either eye in the UK [5].
- Some ethnic backgrounds increase a person's risk of eye disease in older age [7].
- It is estimated that in the UK between 50 to 70 per cent of sight loss in the older population could have been avoided [8].

Health and additional disabilities

- The majority of people over 75 have three or more long term health conditions [9].
- Currently 222,000 people aged over 70 in the UK have dual-sensory loss. By 2015 this is expected to rise to 254,000 [10].
- Up to 70 per cent of people who survive a stroke have difficulty seeing or processing visual information [11].
- At least 123,000 people have both dementia and serious sight loss [12].
- Almost half of all falls experienced by blind and partially sighted people were attributable to their sight loss [13].

Wellbeing

- There is a clear link between visual impairment and reduced psychological wellbeing, particularly amongst older people [14].
- Older blind and partially sighted people are three times more likely to experience depression than those with good vision [15].

Isolation

Older people with sight loss are at greater risk of social isolation than the general population. Older people with sight loss:

- experience more difficulty getting out and about [16].
- are more likely to experience negative outcomes in relation to health, economic wellbeing and social and civic participation [17].

In addition, many older people with sight loss do not regard the use of the internet as an activity that is open to them [18].

Income

Visual impairment in older people is linked to reduced income.

- More than two-fifths of people living with sight loss are in the bottom fifth income bracket for this age group [19].
- Older people living with sight loss are much less likely than those without impairments to own their home [19].
- Sight loss is related to increased likelihood of being without paid employment before pension age [19].

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 [20]. Yet older people with sight loss are twice as likely as those with no impairment to have experienced difficulty accessing health services [16].

Within NHS eye care services:

- More than 60 per cent of total attendances at ophthalmology outpatients' appointments in England are for patients aged 60 years and over [21].
- Cataract surgery is the most common NHS surgical procedure in England [22] and the average age of cataract patients is 75 years [23].
- Recent research has linked people who undergo cataract surgery to correct visual impairment to longer life [24].
- Approximately 9 million over 60s were eligible for an NHS sight test in England in 2010/11, yet only 5.31 million NHS sight tests were claimed for, even though sight examinations are free [25].
- Barriers for older people accessing eye tests include their concerns around cost, especially for glasses, transport problems and local access to optometry, appearance of being foolish or frail, a lack of an appreciation of the importance of an eye test as an essential eye health check and a failure to accept their own risk of eye disease. This is despite the fact that sight is the sense people fear losing the most [25].

Support for independent living

Older people are also the biggest users of adult social care services in England [26]. 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. In England, between 2008 and 2013, 35 per cent fewer

blind and partially sighted people have received council care and support – 48,665 in 2008/09 to 31,740 in 2012/13 [27]. 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.

Approximately 20 per cent of all older people living at home receive domiciliary services [28]. In 2011 the Equalities and Human Rights Commission undertook an inquiry into older people and human rights in home care. Evidence showed that people with sight loss were involved in some of the most disturbing examples of poor treatment.

“I recently had to stop a carer throwing a blanket over service users 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 [71]

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. However the inquiry did hear complaints about carers who were clearly unaware of the needs of people with sight loss and noted that of the 50 service specifications (the contracts that domiciliary agencies work to) submitted, only 17 mentioned sensory impairment or sight loss.

This is echoed in a recent review of undetected sight loss in care homes. The review reported a lack of awareness of sight loss, associated health problems and symptoms amongst residents, families, care home staff and managers [29]. There are approximately 410,000 older people living in care homes [30] and evidence cited earlier shows that a high proportion of these will have sight loss.

However, supporting 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. NICE has recently 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 [31].

It is also important to note the role of carers, family and friends. A survey of carers showed that 20 per cent of cared-for people in England require care because of sight or hearing loss [32]. In RNIB's inclusive society report two thirds of people relied on family or friends to help with travel and shopping and 50 per cent needed someone to help manage their money. This reliance was closely linked to age [33]. Unpaid support contributes billions to the UK economy – it is estimated that 6.4 million people in the UK are providing unpaid care and support and this contribution is estimated to be worth about £119 billion a year [34].

Key professionals

Older people with sight loss are a diverse group and access many different services, some specialist, some not. Key professionals working with this group are:

- Staff in hospital eye departments: ophthalmologists, ophthalmic nurses and Eye Clinic Liaison Officers (where they are available).
- Optometrists.
- All levels of staff working in hospitals.
- Rehabilitation workers employed by local councils supporting blind and partially sighted people with mobility training, re-ablement for independence and support with adaptations. Access to rehabilitation services is not standardised and provision for blind and partially sighted people varies across the UK.
- Social workers undertaking assessments and supporting the arrangement and management of care packages for older people.
- Occupational therapists working with older people including many who have sight loss.
- Primary care services including GPs, district and community nurses.
- Care workers supporting older people in their own homes and in care environments from extra care housing, residential homes to nursing homes.

While some professionals may acquire experience in issues related to sensory loss, additional training is not compulsory for any of the professional groups listed above, apart from rehabilitation workers and those working in eye clinics and optometry practices.

Policy context

Older people's issues fall within the remit of multiple government departments and budgets. The most significant policy areas and reviews are highlighted below.

Changes to health and social care services

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 are under growing pressure and there are many examples of inequality of access to sight saving treatments, and emotional and practical support [35].

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. In a recent RNIB survey of ophthalmology staff, 80 per cent of respondents said their eye department has insufficient capacity to meet current demand [36].

Ophthalmology services will 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. In England, over 50 per cent of health commissioners have introduced arbitrary thresholds to restrict access to cataract surgery [37] rather than following Department of Health guidance that cataract surgery should be offered when the reduction in the patient's sight has a negative impact on their quality of life. This has resulted in a postcode lottery of cataract services and older people living with unnecessary sight loss.

Access to support in eye hospitals also varies. Approximately 50 per cent of eye clinics have some kind of patient support [38], such as funded Eye Clinic Liaison Officer (ECLO) posts or other early intervention support. This figure is a UK average, and coverage in Wales and NI is better than in England and Scotland. 75 per cent of the people given practical and emotional support by ECLOs (employed by the RNIB group of charities) are over 65, and one third of these are living alone. Emerging evidence suggests that support from ECLOs helps increase independence, improve quality of life and emotional wellbeing [39].

A number of key policy reviews offer the sight loss sector an opportunity to shape future provision:

England

2013 Public Health Outcomes Framework for England – includes for the first time indicators for preventable sight loss [40].

2013 Care and Support Bill – proposes carers' assessments, a right to information and advice, and a cap on lifetime care costs. However, the national minimum eligibility threshold could still prevent up to 800,000 older people accessing care and support [41].

2012 Health and Social Care Act – placed new duties on the NHS to promote integration, and transferred public health duties to local authorities in a bid to ensure public health is better integrated into wider community strategies.

Wales

2013 Together for Health: Eye Health Care Delivery Plan for Wales 2013-2018 – a five year plan to improve eye health in Wales and support those living with sight loss [42].

- 2013** The Strategy for Older People in Wales 2013–2023 [43] and the Welsh declaration on the Rights of Older People (currently out to consultation) [44].
- 2013** Framework for Action on Independent Living [45].
- 2013** A framework for delivering integrated health and social care: a proposed framework to improve services for older people – consultation on delivering integrated health and social care in Wales [46].
- 2013** Social Services and Wellbeing (Wales) Bill (currently going through the Assembly).

Scotland

- 2013** See hear: a strategic framework for meeting the needs of people with a sensory impairment in Scotland – draft strategy with a ten year plan which aims to “lever change for sensory impairment services and support and provides a model care pathway to facilitate better working relationships and service provision for users and carers.” [47].
- 2013** The Public Bodies (Joint Working) (Scotland) Bill aims to “improve outcomes for people by providing consistency in the quality of services, ensuring people are not unnecessarily delayed in hospital and maintaining independence by creating services that allow people to stay safely at home for longer.” [48].

Northern Ireland

- 2013** Transforming Your Care: Vision to Action – service proposals from the Minister for Health, Social Services and Public Safety for a “safe and sustainable health and social care service which is fit for the future.” [49].
- 2013** Older People’s Service Framework (DHSSPS) [50].
- 2012** Physical and Sensory Disability Strategy (DHSSPS) [51].
- 2012** Developing Eye Care Partnerships Strategy (DHSSPS) [52].

Housing – helping older and disabled people live at home for longer

Each of the UK countries are working on strategies and action plans for housing. National standards that prioritise access through design principles that include contrast, wayfinding and lighting are especially important to maintaining independence for blind and partially sighted people.

England

2013 Housing Standards review – proposes a three tiered approach for building regulations so that new and altered buildings are safe, accessible and efficient [55].

Scotland

2011 Homes Fit for the 21st Century – includes a commitment to “a substantial increase in the number of homes of all types, including housing to meet the need of disabled people and older people for independent living.” [54].

Northern Ireland

2012 Facing the future: a Housing Strategy Action plan – includes a commitment to meeting housing needs and supporting the most vulnerable in society [53].

Digital inclusion: helping older people get online

Older people with sight loss report difficulty accessing information about services [56]. 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.

England

2012 Digital Strategy sets out how the government will provide the high quality digital services and make sure that older people are able to benefit fully from the increased independence that comes with digital competence [57].

Wales

2010 Delivering a Digital Wales – a framework for action that recognises that many of the digitally excluded in Wales are older people or those with physical or learning challenges [58].

Scotland

2013 Scotland’s Digital Future – emphasises “digital first” which means that organisations will deliver online everything that can be delivered online; recognises that “broadband use by people with visual impairments (42 per cent)... was significantly below the UK average of 70 per cent” and sets out a commitment to ensure that broadband uptake in Scotland should be equal to, or above, the UK average by 2013 [59].

Learning from the evidence base

Preventing unnecessary sight loss

Older people are the largest group living with sight loss in the UK. Evidence suggests that for older people 50 to 70 per cent of sight loss could be prevented or treated [8].

Maintaining eye health should be seen as a key part of ageing well and supporting older people to live an active healthy life. This message needs to be promoted not only throughout the eye care sector but to all agencies that work with older people.

Key actions are being undertaken to improve prevention of avoidable sight loss:

- 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 [60].
- 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. This programme aims to reduce preventable sight loss among patients aged 65 plus and to support GPs to manage patients with eye conditions more effectively. GPs and primary health care teams will be enabled to provide information in accessible formats so that patients gain a better understanding of appointment details, prescription information (including dosage levels) and general practice communication.
- In Wales, the recently published Welsh Government Eye Health Care Delivery Plan includes a range of actions aimed at preventing sight loss, including the development of a new public education strategy, increasing awareness of eye health amongst health professionals, and work with the Care and Social Services Inspectorate Wales to ensure the importance of good quality eye care is promoted in residential care and that regular sight tests are included in individual personal care plans for residents. A prompt to encourage older people to go for a sight test has also been included in the Over 50's Health Check.

Independence

Accessing health and care services

Older people with sight loss, particularly those over the age 75, are often living with up to three or more long term health conditions, making it even more of a challenge to maintain independence, social networks and wellbeing. Many need care and support which needs to be funded, either by themselves or by local authorities.

It will be important to monitor the impact on older blind and partially sighted people of other changes in health and care commissioning. Commissioners must ensure that funding service delivery plans include provision for people with sight loss. RNIB's sight loss data tool provides local information about blind and sighted people and those at risk of sight loss across the UK [61]. This will support commissioners to use accurate information on the eye care needs of their local populations.

Early intervention

Older people are the largest proportion of people issued with a Certificate of Vision Impairment (CVI) as sight impaired (partially sighted) or severely sight impaired (blind) in England and Wales each year. Research undertaken by RNIB suggests that when the certification and registration process works well it can have a positive impact on someone's life and wellbeing. However, delays in this process can cause great distress. One of the barriers is clinicians underestimating the benefits of certification to patients, particularly for older people [62]. The sight loss sector is calling for the adoption of one agreed Adult UK sight loss pathway [63] across health and social care. A national sight loss pathway would aim 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. This pathway draws together some key processes, such as certification and registration, that can trigger timely support that has a positive impact on someone's life and wellbeing.

Rehabilitation intervention, 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. It offers cost savings in terms of preventing loss of independence and reliance on other services [64]. Yet this specialist rehabilitation service is under significant threat. An RNIB report called "Facing blindness alone" [65] shows that in England there is a postcode lottery of provision, long waits before access to services, rationing through use of eligibility criteria, a practice of restricting interventions to six weeks and in some areas charges toward the cost of it.

In Northern Ireland, work has started to implement the recommendations of the Eye Care Partnerships Strategy. Commissioners and service providers recognise the continued pressures on hospital eye services which are characterised by long waiting times for outpatient appointments and an over-reliance on eye casualty.

The decrease in social care provision, increasing charges for care, and the suppression of fees paid from local authorities to independent care providers of both residential and domiciliary care [66] raises concern about future access to and quality of care and support.

Housing

It is estimated that up to 90 per cent of an older person's time is spent in their home [67] 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 funded "Housing Sight" [68], a document that sets out "design guidance on accessible housing for people with sight loss". The associated Development Quality Requirements (DQR 2005) reference "Housing Sight" and housing associations in Wales are required to meet these standards. This has been an important driver for change in Wales and as a consequence many housing associations have worked in partnership with RNIB and other agencies to ensure that they do.

Inclusion

Accessing information

Accessing information becomes increasingly important to older people as they need to make decisions about care needs, 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. Although technology can offer great opportunities for older blind and partially sighted people, acknowledgement of the barriers they face such as cost, access to training and accessibility packages and that technology may be culturally alien, can be the first step to improving accessibility [18]. A full range of accessible information services needs to be provided if risks of further isolation and discrimination are to be avoided.

Getting out and about

Older blind and partially sighted people often rely heavily on public transport or family members to help with travel [33].

There are some moves to address accessibility in transport within a policy context. The rail industry has the Access for All programme that aims to make rail stations more accessible and the British and European regulations RVAR 2010 and the PRM TSI require all train vehicles to be accessible by 2020.

However local authority cuts pose a risk to access to transport. Research by the Campaign for Better Transport found that 41 per cent of local authorities in England made cuts to bus services in the financial year 2012–13 [69]. Age UK found that these cuts meant older people:

- struggled to get to hospital and doctors' appointments

- stayed in, missing social activities
- found it hard to keep up voluntary and charitable work [70].

If older blind and partially sighted people are to avoid isolation, and maintain social networks and independence it is crucial that transport is made as accessible as possible and that local transport services are protected.

What the evidence tells us

As sight loss is so prevalent in the older population, 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.

- Maintaining eye health should be seen as a key part of ageing well and supporting older people to live an active, healthy life.
- Having several health conditions is the norm for older people so it is therefore important that eye health and sight assessment are high on the agenda for all those working with older people, particularly in relation to dementia and stroke or conditions where other disabilities may mask the symptoms of sight loss.
- Access to effective eye clinic support at the point of diagnosis is important to increasing independence, quality of life and improved emotional wellbeing.
- NHS staff working with older people with sight loss should have visual awareness training. RNIB calls for NHS England to create a National Clinical Director for eye care to ensure that clinical leadership is at the heart of NHS decision making.
- The Public Health Indicator and the Royal College of General Practitioners' clinical priority are steps forward for older people's eye health. It will be important to measure the impact so that lessons can be learned for future practice.
- Adoption of the Vision 2020 Adult sight loss pathway would link health and social care ensuring that the outcomes identified by blind and partially sighted people are achieved, from diagnosis through rehabilitation to living confidently with sight loss.
- There should be a universal offer of early intervention support across the UK to all older people who are losing their sight that includes rehabilitation, that is time limited but not time prescribed, is received in a timely manner, is free and made available before any eligibility criteria assessment.
- Eligibility criteria should properly acknowledge the significant care needs of blind and partially sighted people by recognising the unique barriers to independent living that people living with sight loss face.
- All sectors need to ensure that information is available in different formats and media so that information about services reaches blind and partially sighted older people.

- Older blind and partially sighted people need access to training, support and funding for emerging technology that can support reading, communication, navigation and accessing the internet.
- The eye care sector should work together to influence and support regulators and care sector organisations to provide effective eye health and person-centred care to older people with sight loss.

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Further information and links to all the references listed in this section can be found at our Knowledge and research hub: rnib.org.uk/research

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About our evidence-based reviews

This evidence-based review is one of a series produced by RNIB researchers. Each review brings together key research about blind and partially sighted people of different age groups.

The series includes:

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- **older people.**

In addition 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.

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

- **Sight loss UK.** Our annual evidence review, based on 70 key indicators that show us what life is like for people with sight loss, their carers and those at risk of sight loss.
- **Primary research.** We commission and conduct primary research to understand the circumstances of blind and partially sighted people.
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