

## Royal National Institute of Blind People (RNIB) Scotland response to the Scottish Government national conversation to inform a new Dementia Strategy

### Introduction

The Royal National Institute of Blind People (RNIB) Scotland is the country’s leading charity working with blind and partially sighted people. We support children and adults with sight loss and help them to live full and independent lives, campaigning for their rights.

Around 183,000 people live with a significant degree of sight loss in Scotland. This number could eventually double unless we act to prevent avoidable sight loss. RNIB Scotland welcomes the opportunity to respond to this public consultation to inform a new Dementia Strategy.

### 1. What does dementia mean to you and those around you?

Dementia is complex and multi-faceted, affecting individuals in numerous ways. For those people living with dementia and sight loss consideration to reducing the impact of sight loss is paramount in supporting individuals on their dementia journey. Unfortunately, the knowledge and skills to reduce the impact of sight loss when living with dementia are often lacking in health and social care professionals.

Within the last financial year RNIB’s UK-wide helpline received over 500 calls on living with sight loss and dementia. Sight loss and dementia can both often result in social isolation, lack of inclusion in activities with a detrimental impact on mental wellbeing. Some individuals will struggle with the progression of their dementia and given the progressive nature of an age-related eye condition some will struggle with the loss of their remaining vision.

There are three categories of individuals living with dementia and sight loss - those with undiagnosed sight loss, those newly diagnosed, and those diagnosed with sight loss in childhood. Unless appropriate support is given at each stage their dementia journey can be more difficult and stressful with individuals at an increased risk of falls and loss of independence.

#### Undiagnosed sight loss

Those who are living with undiagnosed sight loss and dementia may be unable to communicate changes in their vision because of their dementia. This can result in changes in behaviour, for example, withdrawal from activities. Staff or carers could attribute this to their dementia rather than sight loss. If sight loss was identified appropriate strategies could be applied to support interactions which are so important in slowing down the progression of dementia. It should be noted that nearly 80 per cent of people over the age of 65 living with sight loss. [[1]](#footnote-1) It is essential to support and promote access to eye health care for early diagnosis, appropriate treatment and prevention of further sight loss.

Staff and carers must be able to distinguish signs of sights loss from dementia behaviours. They need to understand the impact of sight loss, how to reduce its impact and reduce the risk of falls which are higher for those living with sight loss than the general population. [[2]](#footnote-2)

Undiagnosed sight loss is particularly relevant for people with learning disabilities who are ten times more likely to have serious sight problems than other people. [[3]](#footnote-3) They will develop dementia and age-related eye conditions at a younger age than the general population. Sight loss is one of the conditions in learning disabilities that needs to be ruled out to support a diagnosis of dementia and to reduce incidences of “challenging behaviour” resulting in costly and potentially inappropriate interventions. [[4]](#footnote-4)

#### Newly Diagnosed

For people living with a new diagnosis of sight loss, the impact of living with two progressive diseases can be traumatic. Many of the strategies for lessening the impact of dementia rely on visual clues, for example, to prompt someone to take medication or lock the door. Often the lack of understanding of sight loss means strategies are applied incorrectly. However, simple adaptations such as using a voice prompt like Alexa to act as a medication reminder or large print signage with a matt covering can overcome these difficulties.

It is essential that people living with dementia be referred for specialist counselling for the emotional impact of being newly diagnosed with sight. Compared to the UK average, people with sight loss report significantly reduced wellbeing including feelings of unhappiness or depression or being “worthless” and lack of confidence. [[5]](#footnote-5) These feelings can often incorrectly be attributed to dementia. Unless the impact of sight loss is better understood, inappropriate costly referrals with poor outcomes will continue.

Referral to specialist rehabilitation services should also be offered to reduce the impact of sight loss and increase independence, alongside the support of dementia specialists to help to deal with the impact of dementia. Living with dementia can mean often other long-term health conditions are overlooked.

#### Diagnosed with sight loss in childhood

There is a lack of understanding how to support someone who has lived with sight loss all their life to maintain their independence.

RNIB’s Helpline has received calls from concerned family members of loved ones in care homes who have been isolated by non-inclusive social activities. This includes being confined to their rooms due to staff fears that a blind person might fall when walking without what may be “unnecessary supervision”. Meals can be left uneaten if staff forget to tell a visually impaired person where their dinner is and how is positioned on the plate.

Some family members are often left confused and unaware of the support available from specialist sight loss services. Others may often battle with care home staff to regain their parent’s or partner’s independence which staff have limited due to concerns about accidents arising from sight loss and not because of the progression of dementia.

RNIB Scotland considers that for the people we support, the sight loss and dementia journey is often misunderstand and inappropriately supported by health and social care professionals.

### 2. What supports work well for you?

There are many examples of how Self-Directed Support (SDS) can allow individuals and their families to make informed choices. However, there are also ongoing misconceptions about how to manage SDS budgets.

More staff training and sharing success stories would help to ensure more people are able to access support that works for them and their lifestyle and which evolves as their needs change. This is of particular importance for those who are blind or partially sighted.

Support should be holistic in its approach and should not attribute everything to dementia. Support works well when diagnostic support workers have received training on sight loss and understand its impact and how to reduce its impact and the specialist support available. The Eye Care Liaison Officer (ECLO) services understand dementia and can support people with sight loss and dementia and refer onto appropriate services. It is also important to have support that understands that the majority of people over 75 have three or more long-term conditions and this can include sight loss. [[6]](#footnote-6)

### 3. What challenges need to be addressed?

The support currently on offer varies dramatically across Scotland. Many people with dementia face lengthy wait times to access support from the Post Diagnostic Support Link Worker.[[7]](#footnote-7)

RNIB Scotland calls for better support for carers of people with dementia including peer support and access to training sessions.

Opportunities for ongoing development and training for staff working in dementia have been limited since the pandemic with priority given to mandatory training in areas such as medication, moving and handling, and Adult Support and Protection. Training, aligned with the Promoting Excellence Framework, should be mandatory. [[8]](#footnote-8) This should not only include frontline workers but also management staff to ensure that the concepts of person-centred care and the principles of stress/distress are embedded at all levels from recruitment, resource allocation and development opportunities.

All healthcare professionals and social services staff should recognise and value both unpaid and paid carers, to empower them to know when to seek onward referral and to signpost people with dementia to the correct support to avoid crisis point admissions to hospital. Investment in this workforce would increase continuity of care, reduce unnecessary and often traumatic hospital admissions, and provide greater support to unpaid carers. As the annual Care Inspectorate returns show, “many parts of the social service sector faced challenges filling vacancies before the pandemic and that this continues to be the case”. [[9]](#footnote-9)

Much of the information about services and support is not accessible to blind or partially sighted people. We need to ensure that all health, social care, and community information in available in a range of formats including, large print, audio, and braille.

There are 26,000 people living with sight loss and dementia in Scotland and there is limited understanding on how to reduce the impact of sight loss on the dementia journey. Appropriate support to access eye health care should be on a par to the support offered for oral care.

Mandatory training should be instigated to ensure that care staff understand that sight loss can be progressive, and that they recognise the signs of sight loss to reduce diagnostic overshadowing and attributing behaviour changes to dementia. Simple interventions can reduce the impact of sight loss and ease the dementia journey.

The Promoting Excellence Framework should be updated to include a more comprehensive section on sight loss covering communication, guiding, mealtime support, Charles Bonnet syndrome (visual hallucinations) and the sight loss environment. The higher incidences of sight loss and undiagnosed sight loss for people with learning disabilities should also be noted.

Completion of the Promoting Excellence Framework Skilled Level should become a compulsory element of the Scottish Vocational Qualification (SVQ).

There is a lack of mandatory sight loss training for social care and health professionals as part of the SVQ qualification although of the 35 optional units, there are 23 units that require an understanding of the impact of living with sight loss and dementia for successful completion. The current SVQ qualification for Social Services and Health Care (SCQF 6) has four mandatory modules and two optional units. Whilst “Support effective communication” and “Support health and safety of yourself and individuals” are compulsory, there is nothing about communication or creating inclusive sight loss environment in the Promoting Excellence Framework.

The “Update eLearning Module” on Turas for NHS Education for Scotland (NES) was created in response to the Scottish Government See Hear Strategy which acknowledges an increased number of older people with sight loss and hidden sight loss. However, this e-learning module does not cover the effect that dementia can have on vision or offer sight loss and dementia strategies for support. Guiding, including wheelchair guiding, mealtime support tips, adapting environment to cover dementia and sight loss, lighting levels for older people, and their effect all need to be added. Physical layout must also be considered. For example, “Poor colour contrast, particularly with inappropriate lighting, can prevent an individual from functioning safely and independently”. [[10]](#footnote-10) For people with learning disabilities, sight loss and dementia can have a major impact on independence and lead to incidences of challenging behaviour.

The “Implementation of Recommendations” from the See Hear Strategy acknowledges sight loss can be slow onset and that early identification can reduce the risk of falls. People living with dementia are at a higher risk of falls too. [[11]](#footnote-11) It calls for training for staff and inclusion of sight loss within mainstream and community care assessments.

As 26,000 people in Scotland are living with sight loss and dementia it is essential that post-diagnostic support workers, memory clinic staff, and social workers can include sight loss within their assessment. Compulsory training should be extended to all relevant Allied Health Professionals (AHP) such as physiotherapists who are involved in rehabilitation after falls.

As highlighted in the Dementia Strategy and Building on the eight Pillars of Support, often diagnostic support workers and Dementia Practice Co-ordinators only become involved in the later stage of care. The impact of sight loss must be considered as an essential component when applying the Pillars.

Building on the Dementia Strategy, early diagnosis for young onset dementia is needed to ensure sign posting to suitable services. People experiencing young onset dementia can have difficulties with visual processing, resulting in sight loss. It commonly affects reading and writing. People with acquired sight loss can lose their digital skills when they lose their sight due to lack of knowledge of accessibility functions. Signposting to sight loss services that can offer support with digital equipment will help to ensure that technology can assist with independence. [[12]](#footnote-12)

The Dementia Strategy aims to support people to live in their homes/supported accommodation longer. RNIB Cymru has developed a Visibly Better Living Certification scheme designed to provide social housing providers and care home staff with the skills and knowledge to meet the individual needs of the increasing number of residents living with sight loss. [[13]](#footnote-13) This could be usefully adapted in Scotland. The certification scheme provides structure and guidance to adapt existing or new housing provision to create environments which are inclusive for people with sight loss and for the embedding of systems and practices that not only support current residents but future residents who acquire sight loss. Residents will benefit from these changes potentially regaining independence, enabling them to stay as independent as possible within their current housing provision for as long as possible. The changes will not only benefit the general population with sight loss but those who go on to develop dementia. It will be cost effective as many of the adaptations will address visual processing difficulties caused by the individual’s dementia.

RNIB can also offer training to health and social care professionals including paramedics who often deal with stressful emergency situations. Online training modules include Module 1 – Understanding the impact of sight loss when living with Dementia and Module 2 – Enhancing communication when living with sight loss and Dementia.[[14]](#footnote-14)

The Care Inspectorate should consider sight loss as a progressive condition to be assessed in line with the Care Standard principles Responsive Care and Support. [[15]](#footnote-15) Clear guidance specifically on these standards and how these should be met for someone living with sight loss and dementia is required. This will ensure that the Care Inspectorate are confident in their assessment that care providers are providing the correct support. Staff understanding of sight loss and ways to support living with sight loss and dementia must be included within the inspection process.

### 4. How would addressing these challenges change lives?

#### Prevention of sight loss and prolonging independence, reducing the need for or increase care service support:

By providing people with dementia, their families, carers, and communities with more information, we will best ensure people live well with dementia. This needs targeted input into the community. Too often funding for initiatives such as “Dementia Friendly Communities” is provided on a short-term basis and instead should be part of an ongoing model of change. This would help to overcome the stigma and misinformation about dementia that unfortunately often still exists and allow for ongoing conversations about dementia.

This in conjunction with the roll out of the “Stars” programme from Brain Health Scotland can help to ensure that there are opportunities for all ages to gain knowledge on dementia.[[16]](#footnote-16)

Training health and social care staff to recognise the signs of sight loss will ensure early intervention diagnosis and where possible treatment; 50 per cent of sight loss is avoidable. Referral to appropriate sight loss services including rehab and specialist support can prolong independence and delay the need for increased care service support. For people with learning disabilities, it will aid diagnosis of dementia and reduce incidences of challenging behaviour stemming from sight loss and costly inappropriate interventions.

#### Reduction in Falls:

Early detection of sight loss and specialist input could potentially reduce the numbers of falls which often lead to devasting consequences for older people. In Scotland 23,100 people with sight loss aged over 65 experience a fall per year. Of these falls, 10,900 are directly attributable to sight loss. Someone living with dementia is up to eight times more likely to fall than someone without the disease.[[17]](#footnote-17)

#### Training will improve the Quality of Life:

The Scottish Social Services Council (SSSC) acknowledges that “a skilled workforce will play a significant role in ensuring that people with dementia, their families and carers experience a good quality of life”. Social inclusion will improve through:

* the participation in adapted activities;
* better communication skills;
* better mealtime support;
* reduced isolation;
* increased mobility through guiding support where appropriate;
* addressing the prevention of independent access to safe spaces in care homes.

These will all add to quality of life for those with dementia. If sight loss is considered within assessments this will ensure an accurate assessment of needs with better outcomes and appropriate interventions.

#### Reduction in stress and distress:

Training paramedics to understand the impact of sight loss when living with dementia can lessen the stress of admissions to hospital. The use of simple communication strategies can reduce anxiety and fear. For example, saying who is providing care, what they are doing, when they are doing it and why, and when staff are entering or leaving a room.

#### Retention of staff:

There is a high turnover of staff in the care sector. The Chartered Institute of Personnel and Development, the professional body for human resources and people development, states that one reason for leaving employment can be lack of training to develop the knowledge and practice the skills they need to carry out their job. Training can improve the way staff feel about their employers. They are more likely to feel valued, perform their jobs above and beyond and adds to job satisfaction. Addressing the knowledge and skills gap can bring the added benefit of staff retention.

#### Consistency in high standard of care:

Making the Promoting Excellence Framework a compulsory element of SVQ and including a more detailed sight loss section with strategies to reduce its impact will help to ensure consistency in care, and a higher standard of care across health and social care services.

Ensuring that the Care Inspectorate has clear guidance on what is required to meet the needs of people living with sight loss and dementia will improve the inspection process, provide constructive feedback and support organisations to strive for improvements.

### 5. What do we need to build on/learn from what has been done before?

We need to build on the commitment provided by the “Five Pillar model of “Dementia Post Diagnostic Support”. According to the model, “Every person with a new diagnosis of dementia in Scotland is entitled to a minimum of one year of [**Post Diagnostic Support**](https://www.alzscot.org/pds) (PDS) from a named person who will work alongside the person and those close to them.”

RNIB Scotland considers that the one-year timescale should be removed. The pandemic, and increasing waiting times, mean that people are often at a more advanced stage when initial contact is made. Early interventions allow people with dementia greater independence and control over their lives. In the current financial situation, this should include information on income maximisation. Support should be available regardless of time post-diagnosis and adapted as the needs of individuals change.

Provisions should also be made for managing comorbidities. From a sensory point of view, this should include more health promotion messages on the need for routine sight tests to identify and manage preventable sight loss. For those who are blind or partially sighted, guidance should be provided to ensure the environment is suitable. Often, simple and low-cost measures can allow an individual to maintain their independence. This might include improving the lighting and colour contrast within the home.

We need to share examples of good practice more widely. For example, the “Housing and dementia framework: A practice framework to support Scotland’s housing sector” is not yet widely implemented within the community outwith dementia specific services.[[18]](#footnote-18) Families, housing providers and sheltered housing are often supporting individuals well into their dementia journey with little guidance or funding on how to manage the home environment.

We welcome the recent publication of guidance by the Care Inspectorate and Healthcare Improvement Scotland on supporting people with learning disabilities and dementia, “Supporting people with an intellectual/learning disability and advanced dementia moving into a care home:Guidance for staff”. [[19]](#footnote-19) We would, however, also add that additional staff training is required to ensure that this guidance becomes embedded into practice.

#### Updating of the Promoting Excellence Framework to incorporate sight loss impact on the dementia journey

RNIB Scotland recommends the following:

* Exploring and expanding different means of training to deliver Promoting Excellence and resources to accommodate a workforce that is time poor;
* Involvement and partnership working with the sight loss sector to build on existing structures within SSSC, SVQ, NES and the Care Inspectorate;
* Building on the Scottish Government Dementia Working Group which involves people with lived experience;
* Ensuring that the sight loss journey is included in all stages of the dementia journey through the involvement of the sight loss sector and actively recruit carers and people with sight loss and dementia in the development of training and resources;
* Considering the recommendations of the See Hear Strategy within the Dementia Strategy;
* Closer working with Care Inspectorate to consider the needs of people living with sight loss and dementia and the knowledge and skills staff require;
* Building on dementia-friendly work via the introduction of RNIB’s Visibly Better certification scheme for Social Housing and Housing Associations.[[20]](#footnote-20) This certification scheme would support the creation of environments that would mutually benefit people living with sight loss and living with sight loss and dementia.

### 6. What else would you like to tell us?

N/A.

### Contact

For further information please contact Gillian Hallard, NHS Engagement Manager (Scotland), RNIB Scotland: gillian.hallard@rnib.org.uk.

1. [Key information and statistics on sight loss in the UK | RNIB](https://www.rnib.org.uk/professionals/health-social-care-education-professionals/knowledge-and-research-hub/key-information-and-statistics-on-sight-loss-in-the-uk/) [↑](#footnote-ref-1)
2. Slade J: (2020) English Longitudinal Study of Ageing (ESLA) secondary analysis. [↑](#footnote-ref-2)
3. Emerson, E., & Robertson, J. (2011). "Estimated prevalence of visual impairment among people with learning disabilities in the UK". London: Royal National Institute for the Blind & Seeability Learning Disabilities Observatory. [↑](#footnote-ref-3)
4. See “A Bridge to Vision Identifying sight loss – Creating opportunity”. (Date?) Evaluation of the impact of Vision champion training, facilitated by Royal National Institute of Blind People (RNIB), and Avenues Practice development lead in Positive Behaviour Support (PBS) and Person Centred Active Support. Showing the impact on support workers and people who are supported in Avenues South East. [↑](#footnote-ref-4)
5. Slade, J. (2019). "Understanding Society: Comparing the circumstances of people with sight loss to the UK population". London: RNIB. Available from: <https://www.rnib.org.uk/professionals/knowledge-and-research-hub/research-reports/general-research/understanding-society>. [↑](#footnote-ref-5)
6. (Barnett et al, 2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. [↑](#footnote-ref-6)
7. [5 Pillar Model of Post Diagnostic Support | Alzheimer Scotland (alzscot.org)](https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/5-pillar-model-of-post-diagnostic-support). [↑](#footnote-ref-7)
8. See https://www.gov.scot/publications/promoting-excellence-framework-health-social-services-staff-working-people-dementia-families-carers/. [↑](#footnote-ref-8)
9. See [Staff vacancies 2021.pdf (careinspectorate.com)](https://www.careinspectorate.com/images/documents/6905/Staff%20vacancies%202021.pdf). [↑](#footnote-ref-9)
10. “Poor colour contrast, particularly with inappropriate lighting, can prevent an individual from functioning safely and independently.” Gray et al, (2007). [↑](#footnote-ref-10)
11. Tobias F. Kröpelin, Jacques C. L. Neyens, Ruud J. G. Halfens, Gertrudis I. J. M. Kempen and Jan P. H. Hamers (2013). Fall determinants in older long-term care residents with dementia: a systematic review. International Psychogeriatrics, 25, pp 549-563. doi:10.1017/S1041610212001937. [↑](#footnote-ref-11)
12. <https://media.rnib.org.uk/documents/APDF_Sight_Loss_and_Technology_Briefing.pdf>. [↑](#footnote-ref-12)
13. See [Visibly Better - Designing accessible housing and buildings | RNIB](https://www.rnib.org.uk/nations/walescymru/how-we-can-help/visibly-better-designing-accessible-housing-and-buildings/). [↑](#footnote-ref-13)
14. See [Understanding the impact of sight loss when living with Dementia - Events | The CPD Certification Service (cpduk.co.uk)](https://cpduk.co.uk/events/14607-understanding-the-impact-of-sight-loss-when-living-with-dementia). [↑](#footnote-ref-14)
15. See [1: I experience high quality care and support that is right for me - Health and Social Care Standards: my support, my life - gov.scot (www.gov.scot)](http://1:%20I%20experience%20high%20quality%20care%20and%20support%20that%20is%20right%20for%20me%20-%20Health%20and%20Social%20Care%20Standards:%20my%20support,%20my%20life%20-%20gov.scot%20(www.gov.scot)). [↑](#footnote-ref-15)
16. [Home | Brain Health](https://www.brainhealth.scot/). [↑](#footnote-ref-16)
17. Allan L.M., Ballard C.G., Rowan E.N., Kenny R.A. (2009) Incidence and Prediction of Falls in Dementia: A Prospective Study in Older People. PLoS ONE 4(5). [↑](#footnote-ref-17)
18. See [housing-and-dementia-framework.pdf (cih.org)](https://www.cih.org/media/oqnbtkaj/housing-and-dementia-framework.pdf). [↑](#footnote-ref-18)
19. ([20221011 Supporting people with a learning disability and advancing dementia - guidance for staff v2.0.pdf (careinspectorate.com)](https://www.careinspectorate.com/images/documents/6862/20221011%20Supporting%20people%20with%20a%20learning%20disability%20and%20advancing%20dementia%20-%20guidance%20for%20staff%20v2.0.pdf). [↑](#footnote-ref-19)
20. See [Visibly Better - Designing accessible housing and buildings | RNIB](https://www.rnib.org.uk/nations/walescymru/how-we-can-help/visibly-better-designing-accessible-housing-and-buildings/). [↑](#footnote-ref-20)