# RNIB Cymru response to Together for a Dementia Friendly Wales 2017 -2022.

## 1. About RNIB Cymru

RNIB Cymru is Wales’ largest sight loss charity. We provide support, advice and information to people living with sight loss across Wales, as well as campaigning for improvements to services and raising awareness of the issues facing blind and partially sighted people.

We welcome the opportunity to respond to this consultation. People with dementia may have existing eye conditions or develop new eye conditions. Dementia itself can affect vision and visual perception, and professionals often miss visual difficulties when a person has dementia. The combination of both dementia and sight loss can have a large and often dramatic effect on a person’s ability to cope with the symptoms of dementia. It is therefore vital that Together for a Dementia Friendly Wales addresses the additional challenges of living with both dementia and sight loss.

We have not answered all of the consultation questions, but have addressed the issues of most relevant to people with sight loss who are also living with dementia.

RNIB Cymru supports Alzheimer’s Society Cymru’s response to this consultation. In particular, we share their concerns that the aims of the strategy are not spelled out in detail, and that the key actions and high level performance measures need to be SMART in order that the impact of the strategy can be effectively measured. We also regret that the opportunity to develop a truly cross-governmental strategy that takes a more holistic approach to supporting the wellbeing people with dementia, recognising that this is not just a task for health and social care, has been missed.

## 2. Sight loss and dementia

There are currently 106,000 people in Wales living with sight loss. The number of people with sight loss is set to increase dramatically in the future, as the population ages. It is predicted that by 2020, the number of blind and partially sighted people in the UK will rise to over 2,250,000. By 2050, that number will double to nearly 4 million (1). Sight loss affects people of all ages, but the prevalence of sight loss increases with age: one in five people aged 75 and over are living with sight loss; this increases to one in tow people aged 90 and over (2).

A recent study into the prevalence of dementia and sight loss found nearly one-third of people with dementia aged 60-89 years also had significant sight loss (3). As the population ages, the number of people with both dementia and sight loss will increase. In care homes, studies indicate a higher proportion of residents may have both conditions.

The sight problems experienced by someone with dementia may be caused by:

* An eye condition, such as a cataract;
* Another health condition, such as a stroke;
* Normal ageing of the eye;
* The dementia itself.

Regardless of an eye condition, or normal ageing of the eye, people with dementia may experience visuoperceptual difficulties that reduce their sight, in particular in relation to:

* Colour perception
* Figure: background contrast
* Identifying depth and motion
* Visual acuity
* Recognising objects and faces.

For example, Posterior Cortical Atrophy (PCA) is a lesser known type of dementia which initially affects vision. The issue for those affected lies in the interpretation of visual information received by the brain. PCA predominantly presents in younger people (under the age of 65).In the early stages of PCA, most people do not have markedly reduced memory, but memory can be affected in later stages. It is not known whether PCA is a unique disease or a possible variant form of Alzheimer’s disease (4).

Sight loss is typically under diagnosed in people with dementia because the signs can be difficult to separate. One condition may mask or be mistaken for the effects of the other and lead to inaction. For example, both sight loss and dementia can cause confusion or disorientation and lead to loss of independence, activities and social contact. Some unusual behaviour could simply be a reaction to sight loss or attempts to make the most of useful vision – for example someone becoming withdrawn, falling more, holding things up close or reporting visual hallucinations. Given the needs of an ageing population in Wales, Welsh Government must consider how this new strategy can address the specific challenge of supporting people with dementia who have either an existing eye conditions or develop new eye conditions. Without this, we do not believe that Welsh Government will be able to meet its’ commitments under the Glasgow Declaration.

## Response to consultation questions

**Q1. Do you feel there should be any additional themes included? (Yes, no, partly)**

Yes. RNIB Cymru believe that awareness and understanding should be recognised as a theme in itself, separate from Risk reduction. In our view, creating dementia friendly communities is not about reducing an individual’s risk of dementia; rather it aims to ensure that people with dementia feel understood, supported and able to contribute to their community. This is an area that has significantly different challenges, which needs to be recognised with a distinct theme. We also believe that this could incorporate actions across a wider range of portfolios, including transport and housing, which are key to supporting people with dementia and sight loss.

**Q2. Within each theme we have identified a number of proposed key actions. Do you feel these are the right ones? (Yes, no,partly)**

Partly, however we do have some concerns in the following areas:

**Risk reduction and delaying dementia onset**

Under this key theme, RNIB Cymru believe that there is a lack of detail about how the increase in the number of people in Wales able to recognise dementia will be achieved. For example, while the strategy refers to public education initiatives and awareness training, it only refers to schools and educational settings. More information is needed about how this will be achieved. As an example, from the point of view of people with sight loss, we believe that a key group to target could be opticians.

**Assessment and diagnosis**

RNIB Cymru would stress thatdiagnostic tests must be accessible to/appropriate for someone with sight loss. For example, consideration needs to be given to any visual element of diagnostic tests.

While we welcome that the draft strategy covers wider health needs, we regret that there is no reference to sensory loss, particularly the need for regular sight tests. RNIB Cymru believes that there should be an additional proposed action in relation to this. A recent study into the prevalence of dementia and sight loss found nearly one-third of people with dementia aged 60-89 years also had significant sight loss; however almost half of the study participants could have had their sight loss corrected by wearing up-to-date spectacle prescriptions (5). This demonstrates the importance of continuing to have regular sight tests.

Diagnosis is important as some eye conditions that cause sight loss can be treated to avoid further loss of vision. Knowing what eye condition someone has may also give you an idea of the kind of sight loss they have and how best to help them manage with the changes in their vision.

There is a common misconception that it won’t be possible to test the sight of someone with dementia. In most cases, an optometrist (optician) should be able to adjust an eye examination to meet the needs of an individual, accurately measure vision and prescribe and update any glasses needed

In particular, it is vital that someone with dementia who is in residential care has access to proper eye tests. There is commonly no routine eye health or vision screening carried out in all care homes. Staff typically have a limited awareness of the prevalence of sight loss in their homes or how to make the most of people’s sight; they lack understanding of the problems caused by vision defects, the vital role regular eye tests can play in the prevention and treatment of common eye problems and simple steps that can improve people’s vision.

Among people with dementia the situation is likely to be worse, as their sight loss may receive even less attention than in the wider care home population (6), yet identifying a problem with their sight could be key to providing the right care and support for that individual. It is therefore important to ensure that staff in care homes understand the effects of sight loss, how to make the most of people’s vision and the importance of helping them access regular eye tests.

**Living as well as possible for as long as possible**

RNIB Cymru is pleased to see that there is specific reference to sensory loss, and that there is a proposed action for HBs and LAs to develop specific actions to increase access for individuals who have protected characteristics. However there is a lack of detail within this. For example, for someone with sight loss and dementia the barriers could relate to a wide range of factors, detailed further in our response to question 3, including: the built environment (be that in hospitals, care homes, day centres, community centres, their own home or elsewhere); transport issues; information in accessible formats about dementia, or community services and the accessibility of services themselves. Therefore we have real concerns about whether this will enable people with dementia who also have sight loss to live as well as possible for as long as possible.

**The need for increased support in the community**

We would stress that to support someone with sight loss to live as well as possible for as long as possible, the involvement of a specialist rehabilitation officer for the visually impaired is vital. Health and social care staff supporting and caring for people with dementia must be aware of these specialist staff, and able to work with them to achieve the best ways of promoting the wellbeing of people with dementia and sight loss.

Hospital staff must also be responsive to any adjustments needed to provide care for patients with sight loss, and capable of meeting requirements under the All Wales standards for accessible communication and information for people with sensory loss (2013), including the need to ensure environments are accessible for people with sight loss.

**Q3. The strategy describes what services should be available for people and their families and carers to live well in the community for as long as possible. What do you think are the key features of this type of service?**

A key feature of the services that are available for people and their families and carers to live well in the community must be the accessibility of such services.

Key actions to achieve this must include:

* information about services being available in a range of accessible formats - someone with sight loss and dementia will not be able to find out the services that might be available if they are not advertised in a range of accessible formats;
* ensuring transport to service locations is either made available, or is well provided for by public transport. People with sight loss may struggle to get to services if there is not transport available, or public transport options are not accessible as people with sight loss often experience barriers in using both bus and train services, or even getting to the bus stop or train station;
* staff and/or volunteers being aware of the needs of people with sight loss and how best to support them. For example, staff or volunteers talking about what is happening: where the person with dementia and sight loss is and where they are going - describing the route while walking may reduce disorientation and increase independence.

Other factors to consider also include (7):

* in buildings, providing good even lighting and trying to eliminate shadows;
* removing ‘busy’ patterns (on walls, furniture or floors) that create visual clutter and removing shiny surfaces that cause glare;
* minimising visual and physical obstacles and changes in floor surfaces or patterns that can exacerbate visuoperceptual difficulties;
* reducing slip and trip hazards – helping people put things away and find them by using clear storage and / or labelling;
* using colours and contrasts to make different areas or items clear: a white plate on a white tablecloth can be difficult to find; white doors in white walls make it hard to find rooms or cupboards;
* making routes between different rooms or places clear – especially in shared housing;
* using clear signs that contrast with their surroundings.
* people need to know where things are and that they are where they left them: leaving things as the person left them can support independence;
* when entering or leaving the room where a person with sight loss and dementia is – tell them.

**Q4. Within the final Together for a Dementia Friendly Wales we would like to include examples of notable practice. If you have any which you would like to highlight, please do so here. Please explain why you think it is an area of good practice eg an evidence base, an achieved accreditation award.**

We would like to highlight RNIB’s Visibly Better Scheme. This is RNIB’s accreditation scheme for supported housing in Wales. Organisations work towards six standards, which focus on different aspects of accessibility, and receive Bronze, Silver, Gold and Platinum levels of accreditation as they progress through the standards.

The standards help supported housing providers meet legal obligations and quality standards, including the Welsh Housing Quality Standard, the Lifetime Homes standard, the Welsh Government Development Quality requirements, duties under the Equality Act 2010 and the objectives contained in the National Tenant Participation Strategy for Wales.

The Visibly Better Scheme makes a huge difference to the lives of tenants. Often the changes are very simple but lead to a reduction in falls and accidents. Although the standards are aimed at improving accessibility for people with sight loss, they benefit a wide range of tenants including people with dementia or mobility problems.

**Q5. Within the document we have highlighted the advantages of using telehealth, telecare and assistive technologies to help people live more independently and safely within their own home. What do you think the challenges and barriers are in making this happen and how could you overcome these?**

We agree that technology supports the delivery of integrated health and social care and can help manage risks, enhance lives, promote independent living and assist and complement care and support. Technology has the potential to improve quality of life and support people to stay in their own home or in a homely setting for as long as possible.

An individual with sight loss and dementia may present with complex requirements and needs. It is vital that any assistive technologies used are a personalised solution appropriate to the individual. People with sight loss and dementia may experience barriers in accessing and using technology because of their sight loss. For this reason RNIB have produced good practice guidelines for using technology to support people with sight loss, available at <http://www.rnib.org.uk/professionals-social-care-professionals-complex-needs-social-care/dementia-and-sight-loss>.

**Q6.Do you think they key actions will provide a positive impact for people based on the following protected characteristics? (Yes, no, partly)**

Partly. As previously highlighted, we are concerned that the aims of the strategy are not spelled out in detail, and that the key actions and high level performance measures need to be SMART in order that the impact of the strategy can be effectively measured. We also regret that the opportunity to develop a truly cross-governmental strategy that takes a more holistic approach to supporting the wellbeing people with dementia, recognising that this is not just a task for health and social care, has been missed.

For example, we welcome recognition on page 27 that provision of services should be equitable and sensitive to particular needs, such as sensory loss, however we feel that the strategy provides little detail about how to achieve this.

Pages 9 and 21 of the draft strategy note that dementia is more common in people with learning disabilities and Downs syndrome. We would add that people with learning disabilities are 10 times more likely to have serious sight problems than other people and are also at greater risk of developing dementia at a younger age, particularly people with Downs syndrome (8). We are therefore particularly concerned that there appears to be little in the strategy about meeting the needs and promoting the wellbeing of this particular group.

**Q9. Sources of information**

In 2014, with funding from Welsh Government, RNIB Cymru published Homes for people with dementia and sight loss: a guide to designing and providing safe and accessible environments. The aim of this guidance is to support organisations and individuals when designing, refurbishing and maintaining new and existing accommodation and other public spaces. It is based on current regulations, guidelines and good practice and is informed by both extensive literature and research gained from specialists in the fields of dementia, sight loss and housing design, housing associations and local authorities, support staff and carers, people with dementia and sight loss and their relatives. It takes in the views of people living in both urban and rural areas of Wales.

The guide is based on the principles of providing a fully inclusive environment that supports people with dementia and sight loss to live as independently and safely as possible. Due to the nature of dementia and the wide and varied symptoms that people experience when they have both sight loss and dementia, there is not a “one size fits all” set of recommendations that will meet everyone’s needs. Similarly, as dementia progresses someone’s needs may change and further adaptations may be necessary. There are, however key principles that can be incorporated when designing and refurbishing housing for people with dementia and sight loss, which are detailed in the publication.

## 5. Further information

For further information, please contact Tess Saunders, Policy and Campaigns Officer.

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## References

1. RNIB sight loss data tool: <http://www.rnib.org.uk/knowledge-and-research-hub-key-information-and-statistics/sight-loss-data-tool>, accessed on 20/3/2017.

2. Access Economics, 2009. Future Sight Loss UK 1: the economic impact of partial sight and blindness in the UK adult population. RNIB.

3. Bowen et al, 2016. The prevalence of visual impairment in people with dementia (the PrOVIDE study), Health Services and Delivery Research, 4, 21 July 2016.

4. Alzheimer’s Association, <http://tinyurl.com/zsjggmk> ,accessed 15/3/2017.

5. Bowen et al 2016. The prevalence of visual impairment in people with dementia (the PrOVIDE study), Health Services and Delivery Research, 4, 21 July 2016.

6. McKeefery and Bartlett, 2010 quoted in Thomas Pocklington Trust,2013, How can care homes “look out” for eye health? Research discussion paper, Thomas Pocklington Trust. Accessed at: [http://pocklington-trust.org.uk/wp-content/uploads/2016/02/RDP13-1.pdf on 20/3/2017](http://pocklington-trust.org.uk/wp-content/uploads/2016/02/RDP13-1.pdf%20on%2020/3/2017).

7. Vision 2020, 2013. Dementia and sight loss: frequently asked questions. Information in this document was produced by the Dementia and Sight Loss Interest Group, led by Alzheimer’s Society, RNIB, Thomas Pocklington Trust and Ove Arup & Partners Ltd, part of the VISION 2020 UK Group.

8. Emerson, E and Robertson, J, 2011. Estimated prevalence of visual impairment among people with learning disabilities in the UK. RNIB and Seeability; Alzheimer’s Society 2015, Learning Disabilities and dementia, https://www.alzheimers.org.uk/info/20007/types\_of\_dementia/37/learning\_disabilities\_and\_dementia, accessed 20/3/17.