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OPHTHALMOLOGISTS



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## Ophthalmic Services Guidance

# Quality standard for people with sight loss and dementia in an ophthalmology department

December 2015

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Date of review: December 2018

## 1. Executive Summary

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Many patients who attend ophthalmology departments also have dementia. This quality standard has been developed to help ophthalmology departments provide high quality care for these patients. It addresses staff training, support to participate in decisions about care, the design of clinical areas, waiting times and appointment durations, provision of information, assessment of vision and referral for support. The breadth of what should be considered in providing care to patients with dementia in an eye clinic requires liaison between all staff, managers, and commissioners of care within the care pathway.

Patients with dementia can benefit from being identified in advance of attending their appointment; staff who have specific training around dementia; and, being provided with support to participate in decisions about care. A pathway for best interest meetings and obtaining informed consent should be identified where patients lose the capability to do so themselves.

The ophthalmology department can be designed and adapted to meet the needs of people with dementia, including lighting, colour schemes, and signage. Shorter waiting times, being offered longer consultation times and receiving accessible information about vision and eye care can be beneficial. If patients cannot use a vision chart then a functional visual assessment is useful to record in their notes. Referral to local support services can be helpful, and issuing a Certificate of Vision Impairment (CVI) (BP1 in Scotland and A655 in Northern Ireland) can facilitate someone being brought to the attention of social care services. The involvement of an Eye Clinic Liaison Officer (ECLLO) or Sight Loss Adviser can be helpful.

## 2. Introduction

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There are estimated to be 850,000 people in the UK with dementia (Alzheimer's Society, 2015). Although 40,000 people aged under 65 currently have dementia, prevalence significantly increases with age. Dementia affects one in six people over the age of 80 years (Alzheimer's Society, 2015). As the demographic trend towards an ageing population continues, estimates suggest that by 2021 there will be over one million people in the UK living with dementia (Alzheimer's Society, 2014a).

Dementia is an umbrella term, describing the loss of cognitive abilities that occur when the brain becomes increasingly damaged over time. The person's ability to remember, understand, communicate and reason, as well as their ability to perform activities of daily living, declines. There are many different types of dementia, with Alzheimer's Disease and Vascular Dementia being the most common (Alzheimer's Society 2014b).

People living with dementia frequently have other health conditions, sight loss being common among these. Sight loss among people with dementia may be caused by:

- an eye condition;
- another health condition, such as a stroke;

- normal ageing of the eye; or,
- the dementia itself.

Estimates suggest that over 120,000 people in the UK experience co-occurring dementia and sight loss (RNIB, 2013). Both conditions collude to make daily life more difficult for the individual, and their carers. Efforts to optimise sight are crucial in order to maximize quality of life; enabling people to retain independence and reduce the risk of falls. This quality standard outlines the vital contribution that ophthalmology departments can make to ensuring that people with dementia receive appropriate eye care.

This standard was produced collaboratively for the Royal College of Ophthalmologists and VISION 2020 UK by the VISION 2020 UK Dementia and Sight Loss Interest Group (DaSLIG) Committee (see Appendix 1 for the list of organisations represented on the Committee and individual members).

The format for the standard set out here broadly follows the National Institute for Health and Care Excellent (NICE) format for quality standards.

Quality standards have been developed for a variety of different aspects of health, public health, and social care.

NICE has produced two quality standards relating to dementia:

- QS1 ‘Dementia: support in health and social care’ covers the care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings.
- QS30 ‘Supporting people to live well with dementia’ applies to all social care settings and services working with and caring for people with dementia.

NICE’s QS1 requires that ‘dementia services should be commissioned from and coordinated across all relevant agencies encompassing the whole dementia care pathway. An integrated approach to provision of services is fundamental to the delivery of high quality care to people with dementia.’

([www.nice.org.uk/guidance/qs1/chapter/introduction-and-overview](http://www.nice.org.uk/guidance/qs1/chapter/introduction-and-overview))

We have drawn on NICE’s dementia quality standards to inform the quality standard set out here and have applied them to people with sight loss and dementia attending an ophthalmology department. Appendix 2 lists the full set of existing standards and documents that have informed this standard.

We would highlight the Dementia Friendly Hospitals initiative which 164 acute and non acute trusts have already committed to ([www.dementiaaction.org.uk/joint\\_work/dementia\\_friendly\\_hospitals](http://www.dementiaaction.org.uk/joint_work/dementia_friendly_hospitals)). The Dementia Friendly Hospitals Charter sets out principles of what a dementia-friendly hospital should look like e.g. provision of training to staff, governance structures and the environment, and recommended actions that hospitals can take to fulfil them. The Charter gives a framework for self-assessment.

### 3. Using this quality standard

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We would encourage all ophthalmology departments to carry out an assessment of the degree to which it meets the quality statements set out. Before embarking on this assessment, we advise that you obtain relevant management backing to support action based on the results. The standard will be helpful for measuring change in a particular aspect of provision over time.

You could benchmark your department's outcomes against other areas in the hospital to see how you compare, or compare your department with those in other hospitals to highlight particular areas for improvement and learn from others' practice. If you have poor results against a particular standard, consider what actions you can take to make changes, whether they are within your control or whether you need to joint work with others to make improvements. If your results are low overall you will want to use them to inform discussions at a senior level, for example around the need for environmental improvements.

### 4. Identifying people with dementia

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In order to implement a number of the quality statements it will be important to know that a person has dementia in advance of their attending your department. GPs should be asked to include information about the extent of cognitive impairment in making their referral as it is relevant to the person's care in the eye clinic and in their best interests (Caldicott Principle 7). GPs should seek consent to do this from the person with dementia. When they do not have capacity, GPs should ask the advice of a consultee, such as a family member, but can override this in the best interests of the patient.

Information sent to patients in advance of their first appointment could include a request to contact the department to alert them that they have dementia and do not anticipate this information has been passed on. A final opportunity to make this known would be upon entering the department. That a person has dementia, and as much detail as possible as to how it affects them, should be recorded and flagged on a patient's record.

The Alzheimer's Society/Royal College of Nursing leaflet 'This is Me' ([www.alzheimers.org.uk/thisisme](http://www.alzheimers.org.uk/thisisme)) is a tool for people with dementia to complete to let health and social care professionals know about their needs, interests, preferences, likes and dislikes and could be used in an eye clinic.

## Quality Statement 1. People with sight loss and dementia receive care from healthcare professionals appropriately trained in sight loss and dementia.

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To note, RNIB UK Practice and Development Team provides training specifically in relation to sight loss and dementia throughout the UK for health and social care professionals and commissioners.

[www.rnib.org.uk/scotland-how-we-can-help-learning-disability-outreach-and-assessment-scotland/complex-needs-and](http://www.rnib.org.uk/scotland-how-we-can-help-learning-disability-outreach-and-assessment-scotland/complex-needs-and)

Email: [training.ukpdt@rnib.org.uk](mailto:training.ukpdt@rnib.org.uk)

### Quality measure

**Structure:** Does your department have a programme of up to date training tailored for healthcare professionals caring for people with sight loss and dementia?

**Process:** Proportion of healthcare professionals working with people with sight loss and dementia who have sight loss and dementia care training.

**Numerator** – The number of healthcare professionals who are trained in care of people with sight loss and dementia.

**Denominator** – The number of healthcare professionals who may work with people with sight loss and dementia.

### What the quality statement means for each audience

**Service providers** ensure that all healthcare professionals are appropriately trained in sight loss and dementia care according to their roles and responsibilities.

**Healthcare professionals** who work with people with dementia ensure they receive training in sight loss and dementia care consistent with their roles and responsibilities.

**Commissioners** ensure service providers have arrangements for training healthcare professionals in sight loss and dementia care.

**People with sight loss and dementia** can expect that the healthcare professionals who care for them will have training about sight loss and dementia.

**Carers of people with sight loss and dementia** can expect that the healthcare professionals who care for the person with sight loss and dementia will have training about sight loss and dementia.

### Data source

Structure: Local data collection.

Process: Local data collection.

## Quality Statement 2. People with sight loss and dementia, and their carers, are provided with accessible information and the support they require to participate in decisions about their care.

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It is important to remember that people with dementia are often able to participate in decisions about their care. Choice and control in decisions can help ensure that the support provided reflects individual preferences and helps retain independence. If this is not possible, because of a decline in cognitive function and reduced capacity to make decisions or consent to care or treatment options, services may need to provide additional support; input from carers or advocacy services may need to be sought to help with decision-making.

When people with dementia lack capacity, decisions made on their behalf under the Mental Capacity Act 2005 (in England and Wales) should be made in line with the accompanying code of practice. Meeting is often helpful; as is having an independent advocate involved in decisions. The involvement of an ECLO or Sight Loss Adviser can greatly help in this situation.

It is important to note that people with sight loss and dementia may have fluctuating levels of capacity and their ability to participate in decisions should be assessed at each attendance. Being unable to participate at one visit does not automatically mean that they will not have capacity at subsequent visits. It may be necessary to offer the patient a further appointment, should the outcome of the initial attendance be unsatisfactory from either the patient or the professional's point of view.

### Quality measure

**Structure:** Has your department made arrangements to ensure support is available for people with sight loss and dementia, and their carers, to participate in decisions about the care of the person with dementia?

**Process:** Calculate the proportion of people with sight loss and dementia, and their carers, who are supported to make decisions about their care.

**Numerator** – The number of people with sight loss and dementia, and their carers, who are provided support to participate in decisions about their care.

**Denominator** – The number of people with sight loss and dementia.

### What the quality statement means for each audience

**Service providers** ensure that protocols are in place to ensure that people with sight loss and dementia are provided with support to make decisions about their care.

**Healthcare professionals** ensure that support is available for people with sight loss and dementia, and their carers, to participate in decisions about their care.

**Commissioners** ensure that services are commissioned that make sure individuals with sight loss and dementia are supported to participate in decisions regarding their care.

**People with sight loss and dementia** can expect to receive support to participate in making decisions about their care.

**Carers of people with sight loss and dementia** can expect that they and the person they care for receive support to participate in decisions about their care.

### **Data source**

Process: Local data collection.

### Quality Statement 3. People with sight loss and dementia, and their carers, can safely and effectively attend ophthalmology appointments.

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Ophthalmology departments are very busy places due to the high demand for treatment. They can be designed or adapted in ways that help people with dementia manage their surroundings, retain their independence, and reduce feelings of confusion and anxiety. People with sight loss and dementia often take longer to move around and can become distressed by noise, confusing signage and crowds. They will often attend with a carer, as will many other patients in the department. Quiet rooms for people with dementia, and a specific pathway for identifying and managing their clinic visit, are often helpful.

In cases where the dementia is of sufficient severity, it will affect the patient's ability to understand attendance procedures and to communicate their feelings and wishes. In some cases a pre appointment visit may help the patient become familiar and more comfortable with the surroundings.

The design and adaptation of clinics to help meet the needs of people with dementia could include changes to, and use of: lighting, colour schemes, floor coverings, assistive technology, signage, wide doorways, colour contrasts, minimising reflections and glare and notice boards. People with dementia need to be identified so that their appointments can be tailored to their needs e.g. that they bring a carer and may need a longer appointment (see also QS4).

#### Quality measure

**Structure:** Is your environment optimised to ensure that appointments for people with sight loss and dementia can be managed safely and effectively?

**Process:** Undertake an audit of how suitable your environment is for people with sight loss and dementia attending appointments; for example by comparing your environment to the Stirling University's Dementia Services Development Centre Virtual Hospital or using their design audit tool (see Appendix 2).

#### What the quality statement means for each audience

**Service providers** ensure that the department's environment is suitable for people with sight loss and dementia.

**Health care professionals** ensure that people with sight loss and dementia are treated in environments that are appropriate for them.

**Commissioners** ensure that services are provided in environments that are appropriate for people with sight loss and dementia, for example, that they conform to the protocols set out in the Stirling University Dementia Services Development Centre design audit (see Appendix 2).

**People with sight loss and dementia** can expect that services are provided in environments that are appropriate for them.

**Carers of people with sight loss and dementia** can expect that services are provided in environments that are appropriate for the person they care for.

### Data source

Process: Local data collection.

## Quality Statement 4. People with sight loss and dementia have a shorter wait in clinic and a longer appointment.

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People with dementia sometimes find it hard to cope with longer wait times in clinic. Consultations with people with dementia often take longer due to their specific requirements. Ideally people with dementia should be identified prior to attending so that a shorter wait time and longer appointments can be scheduled, or a clinic structure can be created to allow flexible appointment times. Appointments need to be individually tailored to each person's needs. Ensuring that the receptionists and clinic nurses identify people with dementia can alert the rest of the team to provide a shorter wait time and a longer appointment.

### Quality measure

**Structure:** Has your department adopted a system to provide people with sight loss and dementia a shorter wait time and longer appointment?

**Process:** Calculate the proportion of people with sight loss and dementia that have a shorter wait time and longer appointment provided for them.

**Numerator** – The number of people with sight loss and dementia attending the department having a shorter wait time and longer appointment provided.

**Denominator** – The number of people with sight loss and dementia attending the department who require a shorter wait time and longer appointment.

### What the quality statement means for each audience

**Service providers** ensure that arrangements are in place to provide people with sight loss and dementia with a shorter wait time and longer appointment when needed.

**Healthcare professionals** offer people with sight loss and dementia a shorter wait time and longer appointment when needed.

**Commissioners** ensure that provision is made for providing people with sight loss and dementia a shorter wait time and longer appointment when needed.

**People with sight loss and dementia** can expect to be offered a shorter wait time and longer appointment when needed.

**Carers of people with sight loss and dementia** can expect that the person they care for will be offered a shorter wait time and longer appointment when needed.

### Data source

Process: Local data collection.

# Quality Statement 5. People with sight loss and dementia, and their carers, receive accessible information about vision and eye health.

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Information should be provided in appropriate, easy to read formats and language matched to the individual’s needs. Large print, Braille, electronic or audio versions may be needed. The NHS Accessible Information Standard ([www.england.nhs.uk/ourwork/patients/accessibleinfo-2/](http://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/)) should be followed.

## Quality measure

**Structure:** Has your department made arrangements to provide, in accessible formats, information on sight loss, eye conditions, treatment and support options for people with dementia?

**Process:** Calculate the proportion of people with sight loss and dementia receiving accessible information about their conditions, treatment and the support options in their local area.

**Numerator** – The number of people with sight loss and dementia receiving accessible information about their conditions, treatment and the support options.

**Denominator** – The number of people diagnosed with sight loss and dementia.

## What the quality statement means for each audience

**Service providers** ensure that accessible information about sight loss, treatment and support options is available to people with sight loss and dementia, their carers, and the staff who care for them.

**Health care professionals** provide accessible information about sight loss and dementia, treatment and support options.

**Commissioners** ensure that services make available accessible information about sight loss and dementia, treatment and support options.

**People with sight loss and dementia** can expect to be provided with appropriate information about their condition, treatment and support options.

**Carers of people with sight loss and dementia** can expect to be provided with appropriate information about the condition, treatment and support options for the person they care for.

## Data source

Structure: Local data collection.

Process: Local data collection.

## Quality Statement 6. When people with sight loss and dementia cannot perform a standard vision test, a functional vision assessment is used.

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People with sight loss and dementia often have visual agnosia and or expressive dysphasia as well as cognitive impairment, which may make it difficult to assess their vision with a conventional vision chart. An assessment of functional vision, as well as their visual acuity if possible, recorded in the notes can be a more accurate tool for deciding on progression of sight loss. For example, recording that they enjoy reading the paper or are driving, can find food on a plate, or are confused in low light levels.

Tools that have been developed for people with a learning difficulty can be adapted for people with sight loss and dementia, such as the one created by SeeAbility ([https://www.seeability.org/uploads/files/PDFs\\_Books\\_non\\_Easy\\_Read/Functional\\_vision\\_assessment.pdf](https://www.seeability.org/uploads/files/PDFs_Books_non_Easy_Read/Functional_vision_assessment.pdf)).

### Quality measure

**Structure:** Has your department made arrangements to record the functional vision of people with dementia at each clinic visit, if required?

**Process:** Calculate the proportion of people with sight loss and dementia whose functional vision is assessed.

**Numerator** – The number of people with sight loss and dementia who have a functional vision assessment.

**Denominator** – The number of people with sight loss and dementia where a functional vision assessment is appropriate.

### What the quality statement means for each audience

**Service providers** ensure that arrangements are in place to record the functional vision of all people with sight loss and dementia, if required.

**Healthcare professionals** can record the functional vision of people with sight loss and dementia if required.

**Commissioners** ensure that services make available functional vision assessment for people with sight loss and dementia.

**People with sight loss and dementia** can expect to have their functional vision tested if required.

**Carers of people with sight loss and dementia** can expect that the functional vision of the person they care for will be tested if required.

**Data source**

Process: Local data collection.

## Quality Statement 7. People with sight loss and dementia are referred to local support services via agreed pathways.

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People living with sight loss and dementia have multi-factorial and complex needs requiring a variety of different agencies to provide coordinated care. Referring or signposting people with sight loss and dementia to local support services such as the memory clinic, general practice, low vision clinic, vision rehabilitation services or voluntary sector providers can greatly help. Certifying an individual as either sight impaired (partially sighted) or severely sight impaired (blind), using a Certificate of Vision Impairment (CVI) (BP1 in Scotland and A655 in Northern Ireland) is a route for someone with sight loss to be brought to the attention of social care services. An Eye Clinic Liaison Officer (ECLO), or Sight Loss Adviser, can greatly help in facilitating this.

### Quality measure

**Structure:** Has your department made arrangements to ensure people with sight loss and dementia are issued with a CVI, if appropriate, and referred to local support services?

**Process:** Calculate the proportion of people with sight loss and dementia who are issued with a CVI, if appropriate, and referred to local support services.

**Numerator** – the number of referrals of people with sight loss and dementia who are issued with a CVI and referred to local support services.

**Denominator** – the number of people with sight loss and dementia attending the department.

### What the quality statement means for each audience

**Service providers** ensure that arrangements are in place for staff to issue a CVI, if appropriate, and refer people with sight loss and dementia directly to local support services.

**Health care professionals** understand and act on protocols for issuing a CVI and referring people with sight loss and dementia to local services.

**Commissioners** ensure that services are set up to support issuing a CVI, if appropriate, and referral from the department to local support services.

**People with sight loss and dementia** can expect to be issued with a CVI, if appropriate, and referred to local support services from the department, when appropriate.

**Carers of people with sight loss and dementia** can expect the person they care for to be issued with a CVI, if appropriate, and referred to local support services.

**Data source**

Process: Local data collection

## References

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Alzheimer's Society (2014b). Types of dementia.

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Accessed 28<sup>th</sup> June 2015.

Alzheimer's Society (2015). Statistics.

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=341](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341).

Accessed 24<sup>th</sup> November 2015.

RNIB (2013). Sight Loss 2013. RNIB, London.

## Appendix 1 Members of the VISION 2020 UK Dementia and Sight Loss Interest Group Committee.

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## Appendix 2 Source documents used for creating the quality standard.

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- NICE (2010). **Quality standard for dementia: support in health and social care' [QS1].**
- NICE (2013). **Quality standard for supporting people to live well with dementia [QS30].**
- Royal College of Nursing (2010). **Improving quality of care for people with dementia in general hospitals.**
- Royal College of Nursing (2013). **Commitment to the care of people with dementia in hospital settings.**
- Royal College of Psychiatrists (2011). **Report of the National Audit of Dementia Care in General Hospitals.**
- The Kings Fund (2014). **Is your hospital dementia friendly? EHE Environmental Assessment Tool 2<sup>nd</sup> edition.**
- The Scottish Government (2011). **Standards of Care for Dementia in Scotland.**
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