# Good Practice guidelines for Vision Support

## Good practice guidelines for Eye Clinic Liaison Officers (ECLOs): People with Dementia

This guide is one of a set of guidelines available for ECLOs. Please go to the website for further information:

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

'Dementia is so much more than memory'

**Agnes Houston MBE**

### Purpose

This good practice guideline is to inform ECLOs about considerations and appropriate support for people with dementia within the eye clinic setting.

There are around 900,000 adults in the United Kingdom with dementia of these 42,000 are under the age of 65 (Alzheimer’s Society 2022). Dementia is a syndrome arising from different conditions which cause abnormal loss of brain cells and damage to their complex connections. Dementia is a life limiting condition which is usually progressive and associated with a wide range of risk factors including ageing. The conditions which give rise to dementia bring about a range of different changes in the brain and it is not uncommon for the brain to be affected by more than one of these conditions. Some of the most common causes of these changes are:

* Alzheimer’s disease
* Vascular dementia
* Lewy body dementia
* Fronto-temporal dementia.

Symptoms in dementia relate not only to the changes in the brain but also to individual responses to these symptoms and the impact of a person’s social and physical environment.

As the majority of people with dementia are older, the experience of co-existing conditions is common. These co-existing conditions will frequently include eye conditions. The changes in the brain associated with dementia itself can impact on vision. These visual changes often go unrecognised even by eye care professionals.

### Key facts

* The experience of dementia is unique to each individual and it will change over time.
* The social and physical environment can impact profoundly on that experience.
* People with dementia often experience eye conditions.
* Dementia can affect vision.
* Professionals often miss visual difficulties when a person has dementia.

It is important to be aware that dementia gives rise to a diverse and changing range of symptoms. These symptoms can be physical, psychological, and cognitive. Support in the following areas may be required:

* Communication – expressing and understanding.
* Orientation – time, place, person.
* Memory – especially for recent events and information.
* Recognition of people and objects.
* Movement and co-ordination.
* Thinking and reasoning about facts and situations.
* Concentration.
* Visual processing (light, contrast, depth perception, complex visual scenes/patterns).
* Susceptibility to stress – lots of people, excessive noise and visual distractions can be especially stressful.

### Key messages

* It is estimated that at least 250,000 people in the UK are living with both sight loss and dementia (Bowen, Edgar, Hancock et al., 2016).
* 80 per cent of people living with sight loss are over 60 years old. The majority of people over 75 have three or more long term conditions (Barnett, Mercer, Norbury, et al., 2012) which may include dementia.
* 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. Almost half of the study participants could have their sight loss corrected by wearing up-to date spectacle prescriptions (Bowen et al., 2016).
* People with learning disabilities are 10 times more likely to have serious sight problems than other people and are at greater risk of developing dementia at a younger age, particularly people with Down's Syndrome (Emerson and Robertson 2011; Alzheimer’s Society, 2015; 2018).
* People with dementia may not be able to tell you about all aspects of their sight loss.
* Even if the person does not wear spectacles or have a known eye condition, they may still experience visual difficulties.

### Sight loss and dementia

* There is a common misconception that dementia is predominantly about memory. Sight loss is therefore often not considered. There is a tendency to attribute changes in the individual to the progression of their dementia rather than other causes resulting in diagnostic overshadowing (Mason and Scior 2004).
* People with dementia may have difficulties with processing visual information which can exacerbate existing or newly diagnosed eye condition.
* Visual Certification Criteria may not always be met if the visual difficulties are related to the visual processing difficulties associated with their dementia rather than an identified eye condition.
* 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).
* Visual misinterpretation and hallucinations may stem from the person’s dementia particularly in association with Lewy body dementia.

### Practice considerations

It is a statutory requirement under the Equality Act 2010 and the Social Care Act 2008 that public sector agencies make ‘reasonable adjustments’ to their practice that will make them as accessible and effective as they would be for people without disabilities.

* Consider if there is a ‘best time of day’ for the person: people with dementia can experience excessive tiredness in relation to coping with their symptoms and may take longer to plan and get ready for an appointment.
* Excessive noise can cause stress or distress. A quiet room should be available for the ECLO appointment, or it may be more appropriate for the individual to attend the clinic when it is at its quietest.
* Minimise interruptions as these can affect the person’s concentration and communication flow.
* Relatives or friends should be welcomed to attend and sit in during appointments. Note the person with dementia may attend with a dementia assistance dog.
* If possible, create the optimum environment minimise "visual clutter" in the room and personal attire. The area for the appointment should be as clutter free as possible and free from complex wall and floor patterns.
* During appointments, additional multi-sensory cues may support the information being discussed e.g., if talking about an aid or adaptation it would be beneficial to show and demonstrate.
* A reminder of the appointment may be required (letter, phone call, e-mail) – note personal preferences for future correspondence.
* If sending letters or written correspondence, it is good practice to add a photo of yourself to aid recognition and provide context.
* Correspondence may also be more readily accessible if sent on coloured paper and/or specific font/size (the preference for this can be very individual but yellow paper frequently works well). Other accessible formats e.g., braille, audio, or large print should also be offered. This should be discussed at the appointment and noted on the individual’s file.

### Stress or distress

People with dementia will often experience stress and may become distressed in unfamiliar environments. This can be exacerbated by noise, crowds, and other sensory distractions.

### What can make a difference?

If you can access information about the person this can help with:

* Personalising your approach
* Enhancing communication
* Establishing a relationship and trust
* Understanding what is important and what will help
* Minimising stress or distress.

This kind of information may be available in the form of a profile document such as ‘Getting to Know Me’ or ‘This is Me.’ These documents can support your interaction with the person as they contain valuable information about the person’s background, connections, routines, and preferences, including what is likely to be helpful to them.

Introduce yourself fully with your name, job title and purpose of your role. This may need to be repeated during future appointments.

Provide a gently paced narrative to the person during the appointment explaining what you are doing and when you are going to do it.

During the appointment, be clear, concise, and calm, ensuring body language reflects active listening. Don’t forget to smile!

Use simple language and short sentences, one idea/question at a time.

It may be necessary to repeat information, or repeat it slightly differently, if the person is unsure.

Be aware of the importance of tone of voice, body posture, facial

expression and how these can be interpreted. The individual may not remember the details of the appointment but will remember their experience.

Allow the individual time to understand and respond.

### Recommendations:

* If as an ECLO you have identified a beneficial way of working with a person with dementia, this should be shared with other staff and appropriate others.
* Adapt the clinical environment or your office space/work environment to reflect the principles discussed above.
* Consideration should be given to the way information on ocular medications, and labelling on ocular medications, will be understood by the person with dementia. This information/labelling may need to be in alternative formats to ensure they are appropriate.
* Referrals should be made to appropriate services if support with medication is required.
* If new glasses or low vision aids are prescribed, suggest they are labelled/marked to identify who they belong to and what activity they are to be used for.
* Emphasise the importance of attending regular eye health tests with local optometrists.
* When making referrals for potential use of aids/adaptations, discuss with the individual and their family/carer to ensure the referral is appropriate and could improve their quality of life.
* Promote the inclusion of vision information into ‘Getting to Know Me’ or ‘This is Me’ personal profiles. These are documents produced by Scottish Government and Alzheimer Scotland, Alzheimer's Society and Royal College of Nursing; completed by the person with dementia, their families, and carers. The information enables staff to provide more personalised support to individuals with dementia.
* Signpost individuals, families, and carers to local support groups and if required, discuss, and refer for a carers assessment.

## Legal considerations

Consent/ Capacity:

Adults are considered to have capacity to consent, including those with dementia, unless legally determined otherwise.

As dementia progresses the individual may become less able to make decisions; this is called incapacity. However, it is not an all or nothing concept and the person may be able to make choices and decisions in some areas of their life whilst not in others. It can be permanent or transient, for example an infection may reduce capacity. It may be affected by the time of the day, such as, when the individual is tired, they may have reduced capacity.

Human rights legislation and the legal frameworks in the UK provide a safety net to prevent the person becoming vulnerable when they are no longer able to make decisions for themselves.

In England, the Mental Capacity (England and Wales) Act 2005 provides this protection. In Scotland there are a suite of Acts:

* Adults with Incapacity (Scotland) Act 2000 this Act protects the financial and welfare aspects this includes protecting the rights of the person when they are ill in hospital. There is also the provision to allow the person to appoint a person to speak for them called a Power of Attorney and in cases where this has not happened a process through the courts to appoint a Public Guardian to look after the person interests
* Mental Health Care and Treatment (Scotland) Act 2015 this protects the person when they are mentally unwell
* Adult Support and Protection (Scotland) Act 2007 supports individuals who are at risk of abuse and harm.

**All the Acts are underpinned by a set of principles that professionals and others must adhere to.**

## Signposting and useful resources

College of Optometrists

The College of Optometrists have produced useful guidance for professional practice on consent. It covers gaining consent, capacity to consent and links to useful information.

Website: college-optometrists.org

RNIB (Royal National Institute of Blind)

Mental Capacity Policy – RNIB Staff can access the policy via RNIB SharePoint

**Alzheimer Scotland**

Provides information about dementia and dementia services within Scotland and has a dedicated digital and technology team.

Website: [alzscot.org](http://alzscot.org)

Helpline: 24 hours **0808 808 3000**

**ADAM (About Digital and Me)**

Information about products designed for and tested by people with dementia and their families.

Website: [meetadam.co.uk](https://www.meetadam.co.uk/)

**Alzheimer's Society**

Provide support in England/Wales and NI. They have a range of dementia information and resources (including useful factsheets) on their website

Website: [alzheimers.org.uk/](http://www.alzheimers.org.uk/)

**Links to Alzheimer’s factsheets:**

[What is dementia?](https://www.alzheimers.org.uk/factsheet/400)

[Learning disabilities and dementia (430LP)](https://www.alzheimers.org.uk/factsheet/430)

[Rarer causes of dementia (442LP)](https://www.alzheimers.org.uk/factsheet/442) (includes information on PCA)

[Dementia and the brain (456LP)](https://www.alzheimers.org.uk/factsheet/456)

[Sight, perception and hallucinations in dementia (527LP)](https://www.alzheimers.org.uk/factsheet/527)

**Dementia Connect support line**

**0333 150 3456**

Monday to Wednesday 9am – 8pm

Thursday and Friday 9am – 5pm

Saturday and Sunday 10am – 4pm

**DSDC – Dementia Services Development Centre**

DSDC have a mixture of design resources from an accessible level through to more in-depth technical publications.

Website: [dementia.stir.ac.uk/resources](https://www.dementia.stir.ac.uk/resources)

**Thomas Pocklington Trust**

[Design of homes and living spaces for people with dementia and sight loss. pocklington-trust.org.uk)](https://www.pocklington-trust.org.uk/sector-resources/research-archive/design-of-homes-and-living-spaces-for-people-with-dementia-and-sight-loss/)

Website: [pocklington-trust.org.uk/sector-resources/research-archive/design-of-homes-and-living-spaces-for-people-with-dementia-and-sight-loss/](https://www.pocklington-trust.org.uk/sector-resources/research-archive/design-of-homes-and-living-spaces-for-people-with-dementia-and-sight-loss/)

## Local resources

It would be beneficial for ECLO's to find out about local sources of support, for example: Dementia Resource Centre's, Dementia Cafes, Day Services, Dementia Nurses, Admiral Nurses and Support Groups.

## Support

### Health and Social Care Skills Development Team

Provide training and consultancy services along with access to resources specifically to support people with dementia and sight loss. These include tip cards on:

* Communication
* Environment
* Eye Health
* Technology
* Sight loss and Dementia Falls Practice Note
* Sight loss and Dementia Technology Practice Note
* [Dementia and sight loss: promoting good eye health - RNIB - See differently](https://www.rnib.org.uk/professionals-social-care-professionals-complex-needs-social-care/dementia-and-sight-loss).

This Effective Practice Guide was written by:

Health and Social Care Skills Development Team

Alzheimer Scotland

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