# Good practice guidelines for Eye Clinic/ Care Liaison Officers (ECLOs)

## Patients who have had a stroke

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)

## Purpose

This good practice guideline is to inform ECLOs about considerations and appropriate support for patients post stroke.

## Stroke statistics

The following are some statistics about stroke from the Stroke Association website:

"There are 1.3 million stroke survivors in the UK."

"100,000 people have strokes each year".

## Visual problems after stroke

It is estimated that 60 per cent of stroke survivors have vision problems immediately after their stroke. This reduces to about 20 per cent three months after stroke (Rowe F (2013).

Care provision and unmet need for post stroke visual impairment. Available: <http://bit.ly/2iMfarz>

(Last accessed 31 January 2023).

Here are some examples of visual problems after a stroke:

### Peripheral visual field loss

Parts of the visual field are affected. An example of this would be that stroke survivors may lose one side of their visual field and can only see the right or left half of what they are looking at. This is called hemianopia and the most common type of visual problem after stroke. (Ref: Rowe F (2013).

Care provision and unmet need for post stroke visual impairment. Available: <http://bit.ly/2iMfarz>.

(Last accessed 31 January 2023).

### Central vision loss

Stroke survivors may not see anything at all or can only see things on the sides of their vision – not the centre. Central vision loss is when the centre of your visual field is affected. ​

### Eye movement problems

Eye movements can be affected by stroke. This can make judging distances difficult and can result in the eyes constantly moving, so that objects seem to wobble. This is called nystagmus. Eye movement problems can also cause double vision (diplopia).

### Visual processing problems

This can cause changes in the way the brain processes the information it receives from the eyes. There are many types of visual processing problems. An example is visual neglect, sometimes called visual inattention. This is when the brain is not receiving information about what the stroke survivor is seeing on one side, so they may not be aware of anything on either their right or left side. This can result in them accidentally ignoring people or bumping into things.

Someone who has had visual loss as a result of stroke may also experience visual hallucinations known as Charles Bonnet syndrome. More information on types of hallucination after stroke can be found on the Stroke Association website:

[stroke.org.uk/effects-of-stroke/hallucinations-and-delusions](https://www.stroke.org.uk/effects-of-stroke/hallucinations-and-delusions#:~:text=Visual%20hallucinations%20due%20to%20a,for%20several%20months%20before%20reducing)

Accessed 20.12.22.

Visual perception problems can be experienced by someone who has had a stroke. For example, the person may have problems recognising things, this is known as agnosia. More information can be found in the Stroke Association publication ‘Problems with memory and thinking after a stroke’ p14-16 by accessing the following link:

[Problems with memory and thinking after a stroke guide.pdf](https://www.stroke.org.uk/sites/default/files/publications/problems_with_memory_and_thinking_after_a_stroke_guide.pdf). Accessed 20.12.22.

Reference for the above information and for further information please access the following webpage:

[stroke.org.uk/effects-of-stroke/physical-effects-stroke/vision-problems-after-stroke](https://www.stroke.org.uk/effects-of-stroke/physical-effects-stroke/vision-problems-after-stroke)

Accessed 20.12.22.

Some visual problems can improve or resolve after stroke, however some are long term/permanent visual difficulties.

Keep in mind that someone who has had a stroke may also have an eye condition from before their stroke or may also develop an eye condition after a stroke, for example age-related eye conditions, e.g., cataract.

## Practice considerations

* Allow more time for the appointment, especially if the patient has communication difficulties post stroke.
* Check most suitable positioning when communicating with the person, to avoid being in a position where they may not be able to see you.
* Consider some tips for supporting people with visual perception problems including optimal lighting, removing clutter, introducing yourself, let them know and remind them where you are, what you are doing and why etc.
* Consider the way information is provided to the person and if required, information on how to use their eye drops. Symbols may be used due to a communication difficulty, aphasia for example. Aphasia is a language and communication disorder. Some stroke survivors may have difficulty processing written language after stroke. Communication aids may be used by the person, for example symbols or pictures.
* Some stroke survivors may have a ‘communication credit card’ to let people know they have had a stroke and may need more time to communicate. More information on communication credit cards and communication tools can be found on Stroke Association website:

[stroke.org.uk/what-is-aphasia/communication-tools](https://www.stroke.org.uk/what-is-aphasia/communication-tools)

* Find out if there is a stroke specific eye care pathway in your area, for example some areas have an Orthoptic stroke clinic within the eye clinics, or screening on stroke wards. Understand local referral procedures, especially if you see a patient who has not accessed these services.
* Find out if there is a process/pathway for working with stroke survivors in your area and if ECLO role is included in this.
* Make links with stroke specific professionals, for example, the Lead Stroke Nurse in the area, Occupational Therapists, the eye care professionals involved in stroke specific eye clinics and ensure they understand your role and how to refer to you.
* Be aware that the person may not be aware of their visual difficulty, depending on where the stroke has affected the brain.
* Offer information in a format which is accessible to the patient, for example, a patient may prefer large print or print in narrower columns, column format, rather than print across the full page if their visual difficulty after stroke is causing reading difficulties.
* Patients who have had a stroke are not allowed to drive for at least one month after the stroke and should take the advice of their medical professional on when they can resume driving. See resources below for further information.
* Find out if there are local contacts within Stroke organisations, for example, Stroke Association or Chest, Heart and Stroke Scotland.
* Offer patient referral to local Peer support / local stroke networks and other stroke groups / helplines. See resources below.
* Refer to Low Vision services or Orthoptic clinic, if appropriate, for strategies relating to field loss.

## Useful Resources

* 'Visual problems after stroke' factsheet from the Stroke Association. This can be accessed on their website: [stroke.org.uk/effects-of-stroke/physical-effects-stroke/vision-problems-after-stroke](https://www.stroke.org.uk/effects-of-stroke/physical-effects-stroke/vision-problems-after-stroke) Accessed 20.12.22.
* ‘Problems with memory and thinking after a stroke’ leaflet from the Stroke Association. This includes information about visual perception problems, including agnosia. [Problems with memory and thinking after a stroke guide.pdf](https://www.stroke.org.uk/sites/default/files/publications/problems_with_memory_and_thinking_after_a_stroke_guide.pdf) Accessed 20.12.22.
* 'Driving after stroke' factsheet can be accessed from the Stroke Association website: [stroke.org.uk/life-after-stroke/driving](https://www.stroke.org.uk/life-after-stroke/driving) Accessed 20.12.22.
* Stroke Association [Communication problems after a stroke](https://www.stroke.org.uk/resources/communication-problems-after-stroke).pdf information leaflet can be accessed and downloaded from Stroke Association website [stroke.org.uk](http://www.stroke.org.uk). Accessed 20.12.22.
* Video resource ‘My Stroke Guide: Sight problems after stroke’ [youtube.com/watch?v=CaJ-mP\_SLKQ](https://www.youtube.com/watch?v=CaJ-mP_SLKQ). Accessed 20.12.22.
* Video resource ‘Thomas Pocklington Trust: What do we see? How the world looks to blind and partially sighted people – Hemianopia’: [youtube.com/watch?v=BxqXEt5tuQs&t=474s](https://www.youtube.com/watch?v=BxqXEt5tuQs&t=474s). Accessed 20.12.22.

## Useful Contacts

* RNIB Website - [rnib.org.uk](http://www.rnib.org.uk). Accessed 20.12.22.
* Stroke Association website - [stroke.org.uk](http://www.stroke.org.uk). Accessed 20.12.22. Helpline **0303 3033 100**, email **helpline@stroke.org.uk**
* Chest, Heart and Stroke Scotland website - [chss.org.uk](http://www.chss.org.uk). Accessed 20.12.22.
* Chest, Heart and Stroke Scotland Advice Line **0808 801 0899**.

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Document ends.