

# Vision care for stroke survivors

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Research on the provision of vision care for stroke survivors with visual impairment was carried out for Thomas Pocklington Trust and the Stroke Association by a team led by Dr Fiona Rowe, University of Liverpool.

The research findings identify the types of visual conditions that occur following stroke, the impact this can have on stroke survivors and recommendations for provision of eye care following stroke.

## Summary findings

- It is estimated that around 60% of stroke survivors experience some form of vision problem such as impaired central or peripheral vision or eye movement abnormalities immediately after their stroke. This reduces to about 20% by three months post-stroke.
- The impact of sight loss on stroke survivors is wide-ranging and can include:
  - Loss of confidence
  - Discomfort, pain, anxiety, depression
  - Difficulty with reading and hobbies
  - Inability to judge distances, increased bumps and collisions, fear of falling
  - Inability to participate fully in rehabilitation, delayed return to work and independent living, loss of driving licence
- Stroke survivors, carers and clinicians reported a need for increased awareness and understanding of post-stroke visual impairment and for information on the subject to be readily accessible. A third of practitioners responding to the survey did not supply visual impairment information to patients or carers.
- UK-wide interviews identified recommendations for improved ways of working and co-ordination for stroke and vision services. They also highlighted weaknesses and threats to current good practice vision care services for stroke survivors.



## Background

Visual impairment is a common consequence of stroke. It has considerable impact on people's daily life which is in addition to the other problems they experience following their stroke. National guidelines across the UK (Royal College of Physicians National Clinical Guidelines for Stroke 2012, Scottish Intercollegiate Guidelines Network Guidance 118, 2010) recommend specialist vision assessment for stroke survivors who are suspected of having a visual problem.

## Research aims

The aims were to identify the vision care provided for stroke survivors with visual impairment and the extent to which they have needs that are not currently being met, specifically:

- How much 'unmet need' (when a problem is not addressed or is not addressed sufficiently) is there in post-stroke vision services?
- Is there a clear pathway for vision care in stroke survivors?
- What are the variations in post-stroke vision care, and how might they be addressed?
- What constitutes good practice in post-stroke vision care?

## Research methods

The project was conducted over a short timescale of six months. A mixed methods approach was used including:

- a systematic literature review
- five full biographical narrative interviews with individuals who had had ischaemic infarcts (strokes as a result of blockage of blood supply), vision problems, and ranged in age from 34 to 75
- contact with a broad range of stroke networks, researchers, stakeholder groups and organisations to identify previous patient or professional surveys or scoping exercises that had addressed vision
- a survey of professionals from eye care and stroke teams
- interviews with professionals e.g. eye clinic managers, nurses and orthoptists in 14 services perceived to be examples of good practice because they had established integrated vision and stroke services. Orthoptists are members of the NHS eye care team and are involved in the diagnosis and management of conditions such as binocular vision abnormalities, childhood vision deficits, glaucoma, low vision and neurological disorders.



## The extent of visual impairment after stroke

The literature search produced 144 articles which were directly relevant to this study. From these it was not possible to identify a precise incidence of visual impairment after stroke. However, based on a combination of prospective cohort studies (where a group of people is followed over a period of time) and clinical trial data, it is estimated that visual impairment occurs in approximately 60% of strokes overall, ranging from up to 51% having visual field loss to around 80% having visual perceptual problems. Dependent on the type of visual impairment, between 17% and 71% of people fully recover, with recovery rates being highest for central vision defects. Vision screening and assessment were less accurate when undertaken by staff who did not have formal eye care training.

## Views and experiences of stroke survivors with visual impairment

Interviews with five individuals highlighted issues with delayed diagnosis of their strokes. If the primary symptoms were visual, the diagnosis was often attributed to other causes such as migraine. Visual impairment added impact to already existing problems, and included loss of confidence, panic attacks and being unable to return to work or pursue hobbies. There was limited support for vision problems and stroke survivors and their carers wanted improved education and access to information to promote awareness of post-stroke visual impairment.

## Views and experiences of professionals

548 responses were received to the survey of professionals, with roughly equal numbers from stroke (e.g. stroke physicians, neurologists, occupational therapists) and eye professions (e.g. ophthalmologists, orthoptists, eye clinic liaison officers). Forty one per cent of respondents said they saw most stroke patients for vision assessment within one week of stroke onset and 57% saw patients on the stroke unit. Vision screening tools were used by 22%. Typical length of follow-up for visual problems was reported as less than three months. Only 46% reported using a care pathway and one third responded that they did not provide vision information leaflets to patients or carers. One fifth of respondents rated their knowledge of vision problems as poor and up to 40% said that the existing evidence base either did not, or slightly, inform their assessment and management of vision problems.

*“I banged into this lady because I didn’t see her and she was extremely rude to me saying what are you doing but you know she didn’t realise I had these hidden disabilities”*

Female stroke survivor in her mid-40s

## Responses concerning unmet need

A number of previous surveys report clear unmet need for visual impairment post-stroke. For example, the Stroke Association's 2010 needs survey of stroke survivors found that 48% had experienced a visual problem, and of these 26% had unmet needs.

## Suggestions for good practice

Clear recommendations for management and service provision of vision care for stroke survivors arose from interviews with staff in integrated stroke and vision services:

- a minimum provision of two orthoptic sessions per week
- named orthoptist on the stroke team
- provision of lay summaries of visual assessments and rehabilitation to stroke survivors
- using standardised screening/referral forms and a clear vision care pathway
- open communication between stroke and eye teams
- vision assessment within one week of stroke onset so that this information can be fed back to the stroke team to influence their treatment choices
- flexible appointment systems, provision of visual impairment information and post-discharge support to be available to patients and carers

## Threats and weaknesses in current vision care services

The interviews with professionals in combined stroke/vision units also identified a number of perceived threats and weaknesses in current post-stroke vision services. These included:

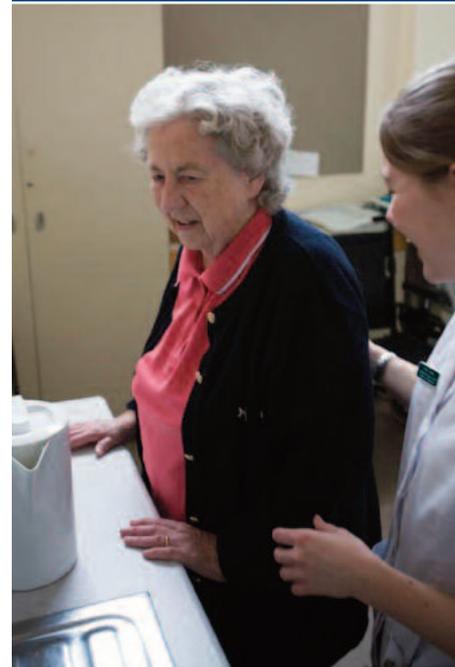
- A lack of funding for good post-stroke vision services
- Where there was an insufficient number of orthoptist sessions, there was a risk of assessments not being made quickly enough or missed altogether
- A lack of orthoptic cover was particularly problematic during holiday periods and staff rotation meant that there was a need for frequent stroke staff retraining by orthoptists
- Where there was a lack of 'buy in' and support for post-stroke vision services from stroke physicians, this meant that these services were more likely to fail

- Occasional misinformation about visual conditions from stroke teams sometimes confused stroke survivors

## Conclusions

- There is still considerable unmet need for vision care in stroke survivors with vision problems
- Estimates of prevalence of post-stroke visual impairment are approximately 60% and the vision problems experienced have considerable impact on activities such as reading, self-care and navigation
- There are variations in how vision screening and assessment is undertaken and in how stroke survivors with vision problems are referred to eye care services. Existing screening protocols, vision tests and care pathways, whether locally or nationally agreed, should be adopted and implemented widely
- Stroke survivors often go without appropriate visual impairment information and there is a need to make this widely available to both them and their carers
- Stroke survivors need early vision assessment so that this information is available to the stroke team to influence their treatment choices
- There is a need for more awareness and knowledge of post-stroke sight loss for professionals dealing with stroke survivors

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## Further information

The full research report entitled '*Care provision and unmet need for post-stroke visual impairment*' is available from Thomas Pocklington Trust on request.



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