Enriching Lives
SeeAbility is the operating name of The Royal School for the Blind. Founded in 1799. Registered Charity Number 255913.

Some people’s eye poking is dangerous, resulting in damage that could lead to blindness. It can be distressing for others to observe and may lead to others not developing relationships with the person. Even ‘gentle’ eye touching often causes eye infections.

Ways to help reduce the risk of damage to the eyes should be based on an understanding of why the person frequently pokes their eyes.

The factsheet includes information from:
Informal surveys
• Advice from blind adults
• Members of the Keratoconus Group
• The special interest group on learning disability and vision.

Thinking about eye poking

Eye poking is often viewed as a form of self-injury - especially by supporters of people with learning disabilities. Self-injury is more common than many people realise.

When people who do not have learning disabilities are asked why they self-harm they usually explain that they use it as a coping strategy as a way of releasing tension when faced with great emotional pain.

Eye poking is often regarded as a self-injurious or dangerous behaviour. However, people with visual impairments firmly state that eye poking or rubbing should not automatically be regarded in this way.

Possible reasons for people with learning disabilities poking or touching their eyes

Eye touching behaviours are part of a group of mannerisms or behaviours sometimes called ‘blindisms’. It may serve to relax, stimulate or reassure the person, just as thumb-sucking, rocking or cigarette smoking may for others.

The light sensitive retina at the back of the eye is able to respond to pressure caused by the person poking the external eye. This pressure causes ‘lights’ to be seen within the brain – even if the person is blind or have their eyes shut. This is known as ‘phosphene entopic phenomena’.

Self-stimulation and entertainment

Many people with learning disabilities and visual impairments are in settings where there is little to occupy them, or no-one to interact with. They may spend a considerable amount of time each day waiting for others to help them.

Eye poking may be one of the few activities that they can enjoy. It can be stimulating and provide visual rewards (within the brain) for people whose lives may otherwise be lacking in colour and interest. It is an activity the person can control.
Eye poking and touching - continued

Sight-threatening eye conditions and sight loss
People may have developed a sight-threatening condition, which needs treatment. There is some evidence that keratoconus (a sight-threatening condition effecting the cornea) is associated with excessive eye rubbing. It is more common in families with a history of allergies.

Even a small reduction of vision can cause distress, causing people to touch their eyes more often than before.

Hay fever and allergies
People may have itchy eyes from unidentified hay fever or allergies. For some people the ‘hay fever season’ lasts from April to October, making their eyes really itchy for months on end. People may have other allergies too.

Eye infections, eyelash, eyelid and skin problems
Some people have frequent eye infections. These infections can make the eyes feel itchy or sore, increasing the likelihood of people touching or poking their eyes.

People may have in-growing eyelashes, which can severely damage eyesight. These may need to be removed by an optometrist or nurse.

People with certain conditions (such as Down’s syndrome) are also prone to blepharitis and other problems that cause inflammation of the eyelids.

Scaly eyelids, bumps or cysts on the eyelid can all be irritating or painful. People often need help to clean their eyelids and apply eye ointment. People may also have skin problems on their eyelids or close to their eyes, such as psoriasis, eczema, dermatitis.

Dry eyes
caused by:
  • air-conditioning
  • looking at computer screens for long periods
  • hormone replacement therapy
  • eyelid problems

Glasses
Wearing the wrong glasses can make people touch their eyes. They need the correct prescription.

Tiredness
Most people rub their eyes when they are tired.

Stitches not being removed after eye surgery
Stitches deliberately left in place by the consultant may be annoying and uncomfortable.

Self-injury associated with syndromes or neurological problems
Some people have a genetic condition or biological anomaly which is linked to self-injury or a lack of awareness of pain - although this link is not fully understood.

However, it should never be assumed that eye poking or eye touching has been caused by their syndrome. Behaviour must always be observed and any intervention be based on the assessment made.

Eye poking behaviours have occasionally been reported in people who have cortical problems or acquired brain injury. Assessment by a neurologist is required.

Communication or attracting social attention
Eye poking may be a way of gaining attention that the person desperately needs. It may be a means of communicating - for example, if someone rushes over every time a person pokes their eyes, this is a successful way of the attention the person needs.
Strategies for Supporting people who poke their eyes

Most people rub or touch their eyes from time to time and do so for many reasons. Sighted and visually impaired adults with learning disabilities also poke or rub their eyes. Some people with learning disabilities may do so more intensely and for reasons that might be difficult for other people respond to or understand.

Some people's eye poking is dangerous, resulting in damage that could lead to blindness or their eye having to be removed. It can be distressing for others to observe. Even 'gentle' eye touching often causes eye infections.

Support Strategies: Observing and recording

Many people with learning disabilities cannot explain why they frequently poke or harm their eyes.

It is not always clear when 'mild' eye poking becomes a major health risk to the person - so it is important to observe people who regularly poke, touch or rub their eyes. Observing people will lead to a greater understanding of why people poke their eyes.

- Always record your observations and share them with others.
- Regularly look to see if the person’s eyes are healthy or are they blood shot, inflamed etc?
- Also check eyelids, eyelashes, for styes, cysts or skin problems.
- Watch what the person is actually doing, how frequently and how intensely.
- Ask others if the person has done this in the past, or if it is a new behaviour. Changes in behaviour indicate that their sight has deteriorated. Even a small reduction in vision causes distress.
- Discover if a person suffers from allergies / hay fever.
- Establish if a person is more likely to touch their eyes at a particular time of day.
- Watch if there are particular situations when people are more likely to poke or touch their eyes. Are they bored, upset or lonely?
- Does the person use eye poking as a method of communication – does it attract the attention from others?
- Is the person very upset and why? What is their behaviour communicating? Does the person need additional help urgently?

Support Strategies: Considering eye care and general health needs

Minimise the risk of a person damaging their eyes:

- The person’s hands should be kept clean – consider using anti-bacterial hand wipes to the fingers and nails. Fingernails need to be kept clean and short, with rounded ‘corners’ to reduce the risk of scratching eyes.
- Supporters need to ensure that their own hands are clean and should always apply universal precautions before supporting others.
- People with learning disabilities need regular eye tests and health checks.
- Ask about recent eye tests. What did the optometrist find? Were glasses prescribed? When should they be worn and does the person wear them regularly? Are glasses kept clean? Has the person been referred to an ophthalmologist?

Have you or others acted on any recommendations – have you referred to the person’s GP any health concerns?
Support Strategies:
Interventions to consider

After observation and assessment it may be agreed that the person's eye poking is likely to have a serious impact upon their eyes and vision. If this is the case they will require skilled intervention to reduce the impact of their behaviour upon their eyes and sight.

As well as contacting Eye Care specialist and the person's GP you should consider seeking the advice from Communication specialists, behavioural support teams, specialist workers for the visually impaired and skilled support staff.

Some practical advice follows:

- If you believe that people eye poke to gain social attention and companionship – provide this on a regular basis – don’t wait for the person to eye poke before engaging with them.
- With the person’s consent consider holding or maintaining some gentle contact with the person’s hands whilst communicating with them. This might provide distraction.
- If you believe that the person is bored increase activity and engagement – but be sensitive to not overloading a person’s day.
- Consider introducing activities that provide visual and sensory rewards – preferably those that occupy the person’s hands.
- Ensure people understand what is going on around them.
- Reassure people at times of stress or when settings might be confusing.
- Consider different ways to help people take more control and exhibit choices.
- Developing and extending people’s communication skills.
- Some people might be able to understand the impact their behaviour has on others – they may stop or reduce eye poking in social settings. Some people may assert their right to poke their eyes.

Staff will need training to work successfully with blind and partially sighted people with learning disabilities – especially those supporting people whose behaviour may be hard to understand.

The use of splints

We have sometimes been asked if it is appropriate for the person to wear arm-splints to prevent damaging their eyes. Splints are a form of restraint, used in the past but seldom recommended now. Restraining a person with splints is almost certainly a violation of an individual’s human rights. People wearing splints frequently learn other ways to touch their eye or self-injure. These new behaviours may place the person at even greater risk.