

Nystagmus Information Pack



Part 4. What to expect at eye
clinic appointments and
terminology explained

WHAT TO EXPECT AT EYE CLINIC APPOINTMENTS

If you or your child has nystagmus, your eye care team is likely to be a multidisciplinary team consisting of different professionals with different specialties and skills. Ultimately the aim is to conduct a detailed examination of the eyes, and sometimes the brain and other parts of the body. This is to enable the nystagmus to be diagnosed and to find out whether there is an underlying cause of the nystagmus, as well as if there are other eye conditions present.

Preparing for your appointment

You should bring along to your appointments any glasses or contact lenses you have been prescribed or are using. It can also be helpful to bring the written prescription for these if you have them.

During your appointments you will be asked questions about your eyes, your vision and your health, as well as about your previous medical history and your family's medical history. Some people find it useful to have written down some information before their appointment.

As you may also have questions you would like to ask at your eye clinic appointments, you may find it useful to write these down beforehand.

At the eye clinic

As many different investigations can be performed, often taking time and requiring specialist equipment and clinicians, it is possible that not all parts of the investigation can be done on one day. Additionally,



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it is important to gather clinical information on more than one visit and to see if anything is changing over time. For these reasons, clinical information is usually gathered over a number of visits to the eye clinic. On some occasions, you may be required to attend a specialist centre for tests if they are not available locally.

Typical clinical information and investigations that are likely to be performed at the first clinical visit and follow up clinical visits include:

- Detailed medical history of the patient and the family
- Vision tests using standardised clinical measurements, appropriate to the age and ability of the patient
- Assessment of eye alignment and eye movements
- Assessment of the nystagmus, which may include eye movement recordings
- Assessment of whether the eyes work together as a pair, or are used independently
- Measurement of the shape and focusing power of the eyes (glasses test). In young children, and sometimes in adults, this will require eye drops.
- Assessment of the health of the eyes, which includes looking inside the eyes. This requires eye drops.

Other investigations that may be recommended include:

- Electro-diagnostic testing and ophthalmic imaging which assess the functioning and structure of different parts of the visual system in detail



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- Brain imaging to look at the structure of the brain and eyes in more detail

'Vision tests' can include a wide range of different measurements using clinical and functional assessments of vision. It can be important to compare different measurements of vision, for example clinical measures may be compared to more 'real life' measures. Vision tests are often repeated to gain more information about how the nystagmus is affecting vision. For example, vision with both eyes open may be repeated and measured with each eye separately; vision may also be measured in different head or eye positions, and measured at different distances.

Members of your eye care team include:

Orthoptist – An orthoptist is a specialist in assessing vision, how the eyes work together as a pair and eye movements. You will often see an orthoptist as part of your eye clinic visit, and will often see them first. The orthoptist will diagnose lazy eye (amblyopia), squint (strabismus) and other eye movement problems that may occur, as well as nystagmus.

Optometrist - also known as an ophthalmic optician. Optometrists specialise in assessing eye health, as well as the need for glasses or contact lenses, so they will diagnose whether you or your child is short sighted, long sighted or has astigmatism. If glasses or contact lenses are necessary, the optometrist will prescribe these.

Ophthalmologist - a doctor specialising in eyes. The ophthalmologist is responsible for the overall management of eye care. They will check the health of the eye and investigate any conditions that may be associated with nystagmus. They may also



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request further investigations to help diagnose the type of nystagmus present.

An eye clinic appointment, when you see all the above members of the eye care team on the same day, can last approximately 3 hours. If you are having additional tests on the same day, your appointment may last longer. Before your appointment your eye clinic should be able to advise you how long your appointment is expected to last.

Eye drops

Eye drops are used in the eye clinic to enlarge (dilate) the pupils, the black part in the centre of each eye. This is often necessary when seeing the optometrist or the ophthalmologist. Eye drops are only used when they are clinically necessary and may not be required at every visit.

The eye drops typically used, temporarily enlarge the pupils and stop the eyes being able to focus on objects that are close. Eye drops usually take 20-30 minutes to take effect. Near vision will be blurred for 3-4 hours and the pupil will be large for approximately 24 hours afterwards. During this time the pupils can't react fully to bright light, allowing more light into the eyes, which can feel dazzling. It is therefore often suggested to bring sunglasses or a sunhat/cap to an appointment if eye drops may be used, as these block out some of the light. These make it more comfortable until the eye drops have worn off.



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Other health professionals

There will be times when a person with nystagmus needs to see another health professional, who does not specialise in eyes or vision. They may detect the presence of the nystagmus as part of their assessment, so it will be useful to them if you explain what the nystagmus is, whether it has changed and the name of an ophthalmologist they can contact for further information if it is required.

TERMINOLOGY EXPLAINED

Acquired nystagmus - nystagmus that develops later in life, after early childhood.

Amblyopia – often called 'lazy eye'. Amblyopia is decreased vision in one or both eyes due to abnormal development of vision in infancy or childhood. In amblyopia, there may not be an obvious problem of the eye. Vision loss occurs because nerve pathways between the brain and the eye aren't properly stimulated. The brain 'learns' to see only blurry images with the amblyopic eye, even when glasses are used. It is the leading cause of vision loss in children and needs to be identified and treated in childhood. Amblyopia treatment typically involves the use of eye patches or atropine eye drops. These may be used in combination with glasses.

Amplitude - a description of the size of nystagmus movement

Beat direction - a description of the direction of the fast phase of a jerk nystagmus



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Binocular single vision – the use of both eyes together as a pair. Binocular single vision usually results in three-dimensional (3D) vision, allowing us to see depth.

Dampens on convergence – when a person looks at an object close to them, their eyes converge. This movement brings both eyes in towards the nose. Some types of nystagmus decrease in intensity (the wobble reduces) when the eyes converge, typically leading to better vision. This reduction of nystagmus when the eyes converge is described as 'dampens on convergence'.

Extraocular muscles - the muscles around the eyes. There are six muscles that attach to the outside of each eyeball. The muscles around each eye usually work in a coordinated way to move the two eyes together.

Fast phase and slow phase - a jerk nystagmus is a type of nystagmus pattern with continual fast eye movements (called a fast phase) and slow eye movements (called a slow phase). The fast phase makes the eyes look like they are beating in a certain direction. The slow phase makes the eyes look they are drifting in the opposite direction. This combination of a slow phase (drift) and a fast phase (beat) in the opposite direction is the rhythmical jerk nystagmus movement.

Frequency - a description of the speed of nystagmus movement

Idiopathic - a condition occurring with no known cause

Infantile nystagmus - nystagmus occurring at birth, in infancy or early childhood.

Intensity - a description of the combination of the amplitude (size) and frequency (speed) of nystagmus movement



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Jerk nystagmus - also known as 'jerky'. A type of nystagmus with continual and repetitive fast phase and slow phase eye movements

Head posture – a person who holds their head in a specific position to look at something, rather than straight, is often described as using a 'head posture'. A head posture is typically used to place the eyes in a position of best vision, utilising the null point. Head postures are often described as either chin up or down, face turn left or right, or head tilt left or right. It may also be a combination of these movements (example: chin down and face turn right). A head posture may be used most when looking at distant objects, however it may change for different visual tasks and for different distances.

Null point – this is a position in which the intensity of the nystagmus is the lowest and the vision is often clearest

Nystagmus - involuntary, repetitive, rhythmical movements of the eyes

Oscillopsia - when a stationary object is seen to move or shake

Pendular - a type of nystagmus that is not jerky. There are no fast and slow phases. The nystagmus is a continual repetitive eye movement in opposite directions, but of the same frequency.

Refractive error – When the shape of the eye does not bend (refract) light correctly it results in a blurred image. The main types of refractive error are myopia (short-sightedness), hypermetropia (long-sightedness), and astigmatism (where the shape of the front of the eye is more rugby ball shaped than football shaped). Refractive error is often described as a need for glasses and is typically corrected with glasses or contact lenses.



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Retina - the layer of light sensitive cells at the back of the eye that are used to detect light and see

Strabismus – sometimes also called “squint”. Strabismus is a misalignment or a turn of one eye, which can be the eye turning in or out, up or down, or a combination of directions. Strabismus can occur with nystagmus.

Surgery - an operation. Surgery may be appropriate in some cases of nystagmus, when performed it is typically on the extraocular muscles.

Visual Acuity (often abbreviated to VA) – the ability to discriminate detail, also referred to as best level of vision. Visual acuity is assessed and measured using different clinical tests appropriate for the age and ability of the patient.



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