

NYSTAGMUS AND READING

Use and training proposals when it comes to involuntary eye movements in children and adults

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We do not know so much

Most people with nystagmus or involuntary eye movements are born with it or they rather have this condition from early childhood for various reasons. In systematic low vision training, *nystagmus* has long been one of the groups which have been trained.

These persons have been trained to use their residual low visual acuity to improve their visual ability or rather their ability to see (Bäckman-Inde: *Low Vision Training*, Liber-Hermods, 1975, Inde: *Low Vision Training (Swedish Synträning)* (edited version), Indenova, 2005). A more specific and scientific description is made by Lappin, J. Tadin, D. Nyquist, J. & Corn, A. L. (2009). *Spatial and temporal limits of motion perception across variations in speed, eccentricity, and low vision*. *Journal of Vision*.

However, there is a lack in concrete compilations of the clinical experience that have been collected over the years by eye doctors, orthoptists and low vision therapists through their work with children and adults with visual impairments.

Out of the 17 children who took part in Project SEE MORE at Lund University (Inde, K et al, *Low Vision Training – Methods and Means for Children with Reduced and Low Vision*, Certec, LTH, 2005), 14 had some form of nystagmus. It could be vertical, horizontal, and rotational and in some cases combined with wave shaped movements (undulating nystagmus). The children were encouraged to use their vision in various ways, and focus was made on their ability to use a hand held telescope in order to expand their visual reach, and also to develop what we labelled as their visual desire, visual strategies, visual efficiency, visual memory and visual confidence with other visual functions at the same time.

It could certainly be said that nystagmus is an unexplored area, where a number of techniques which have not been thoroughly tested are recommended in the clinical work with children. A lot of these methods should – if possible – be verified through scientific testing. But in lack of reliable and evidence based studies, clinical findings can act as a shot in the dark that sometimes hits its target.

This is why I have attempted to summarize the most prevalent thoughts and which have been applied for nearly 40 years to enable children at the youngest feasible age and adults where and when possible, to use their vision for longer periods of time despite their nystagmus in a more efficient way. Please view the presentation below as a number of alternative possibilities to explore and benefit from, or discard.

Shared knowledge in an expanding tool-box

“Audio bio-feedback” is a scientific method which has been documented and discussed. Perhaps it is a method that helps some persons with nystagmus at a certain point and time. However, in this context it is not about limiting the nystagmus, but about controlling it and compensating for the nystagmus that already exists that is being discussed.

The most important attitude is discussed in the book *See Bad Feel Good (inde, K, Indenova, 2003)*: If you do not accept your problem as it is, then you have a problem. But if you accept your visual limitations and conditions as they are, then you can do anything you want since you are in the right lane in life.

Try whatever you think works and see how it goes

My point of view in relation to low vision training after the acceptance of the problem as it is has always been that you have to try to find or develop something new or promising in order to “see how it goes”. After all, the primary aim of research about training achievements is to obtain new knowledge. You will eventually be better off, if you explore and develop new ideas and methods recommended to you.

If you try, assess and develop methods in a creative way in a multi-professional team, the results might also be better than if you do it by yourself. All individuals are different, and it is fruitful to have many tools in your box when you meet persons with nystagmus in your low vision clinic. Shared knowledge can be twice as useful. (*Side-by-Side Design*, Certec, Lund, 2005, Jönsson, B, Inde, K. et al.)

Ideas - not principles

The following methods or ideas of how things could be done have been listed in a presentation that I have used many times both nationally and internationally, but they have only existed as bullet points and not been written down like this. I will take these bullet points and present them one by one, with the hope that they will be discussed among parents, adult nystagmus persons, children, eye doctors, teachers

and others who want to achieve what Anne L. Corn described as “expanding visual reach” for children, with and without optical devices.

In adults, I have many times seen that a small change of behaviour makes reading or seeing through a monocular much more comfortable and more efficient. If only it makes a person less tired, it has been worth the effort, since it is hard to teach a person with low vision and old habits to change from the old method to a new better method of reading. We are not very likely to change, unless the pay-off is evident. And even then, *things take time*.

A common philosophy helps reach goals

However, it is a known fact that if you are able to see more, you will better understand contexts, dimensions, concepts, objects, people and how it all fits together. You will also be able to see more of the world from a longer distance, which is enriching as well. If more endurance could be added, then it is an even greater victory. In Project PAVE (Providing Access to Visual Environment, Vanderbilt University, Nashville, USA) and the parallel Project See More (Lund University, Sweden 2003-2005) we used a philosophy with great bearing in this context:

“Pupils in school with impaired vision should have access to well tested devices. At the same time, they should receive good and constitutionally protected education. Children with useful, functional vision and who have yet to learn how to use it should get help to do so in a meaningful way and then develop their vision further with the devices they need.”

Thus, according to this philosophy there should be effective methods to develop the functional vision, not the visual function. In line with this thought, one must consider the possibilities in relation to the existing limitations. One starting point is of course that “it is not harmful to use your eyes” (Birgitta Bauer, ophthalmologist statement in *Low Vision Training* (edited version), chapter 1, 2005). Another is that behaviour which generates more eyes trembling or nystagmus must be avoided. Presented below are the suggestions onto which several other possibilities could be applied. However, these recommendations should be considered as starting points or inspirations which work very well in particular cases, but which may need to be adjusted in others where the individual's abilities and needs differ from the rule book.

Read on and find out what you think of the list of ideas or suggestions, starting from finding the best possible position of the eyes.

First - find the right gaze position

The discussion with a child or an adult patient could be started off by asking them if they know which gaze position they prefer when using it for a long period of time. Sometimes this gaze point is referred to as the absolute null point, which means that nystagmus then is close to zero. This occurs in some cases, but not all the time. If there is no such gaze position, or if the patient or you as their advisor want to try something new, one can choose from eight different positions and test where the nystagmus, or the frequency of the eye trembling, is at its lowest.

1. Up to the left
2. Up to the middle
3. Up to the right
4. To the left
5. To the right
6. Down to the left
7. Down to the middle
8. Down to the right

In order to make it easier to jocularly decide where the least movement can be found, the nystagmus can be increased by occluding one eye. This will in many cases reinforce the frequency of the nystagmus and make it much more difficult to see. Consequently, this is not recommended to do for a longer period of time.

Move the text and the head when reading – not the eyes

When sighted read, they move their eyes with short, quick saccadic eye movements with pauses. The reading takes place during the pauses or fixations. The movements between the fixations are called fixation movements and line changing is referred to as reversion movements. The fixations make up 95 % of the reading time, 4 % is made up of fixation movements and the remaining per cent is made up of line changing. This means that the fewer fixations you have, the faster the reading speed will be. As a consequence of this, there are obvious reasons to expand the fixation fields. However, there is no point in patients with nystagmus trying to control their eye movements. The nystagmus will often increase. In most cases it is not meaningful to “read like sighted persons do”, if you have nystagmus whereas you cannot control the eye movements and if you do - they will tremble even more.

Instead you should – start with the best gaze position – move the head in saccadic head movements. The movement of the head overtakes the fixation movement of the eyes. Once you manage this you can move the paper with the text at the same time with opposite movements, i. e. you move your head from left to right and the paper with the text from right to left. This technique will take a week or two to learn, but in

the long term it is about maintaining the behaviour, in particular when it comes to achieving better reading speed, comfort and endurance.

One way to achieve these new movement patterns when reading is to start reading from a distance. For example, you could write short words on a whiteboard and let the patient read these by moving his or her head using the best gaze position. This will provide an understanding of how it might work at close up reading. When you start reading from the right distance (depending on the magnification need), you can also start to use exercises which exaggerate the movements you need to practice, eventually adding the fixation movements with the head.

The next step could be for the patient to hold the text and learn how to read with synchronized text and head movements. This is said when patients use head-mounted magnification devices but of course many persons develop other solutions. In many countries large print is used for low vision students, and then you do not need or need less magnification. Hence, the countries using large print will make their students addicted to larger letter instead of bringing their own magnification in the frames or in the pocket.

An alternative issue is when you use hand held magnifiers. Then you don't use movement of the text since one hand is occupied with holding the magnifier. If a person can use saccadic eye and head movements looking through a hand held magnifier that is moved, then in some cases it has been found to be faster for some persons trained to do so.

There are no rights or wrongs - there are just so many ideas to be tested and see "what is the best for me". Also, you can use a magnifier for reading short notes, and the reading glasses when reading longer passages.

Avoid occlusion

As mentioned in the first bullet point, it is not practicable to cover (occlude) one eye since it will seriously increase the eye trembling. We did however find, during the SEE MORE project, that it is not better to use binocular telescopes. The primary reason for this is probably that patients with nystagmus do not have binocular vision. You do not gain anything from using both eyes at the same time since it is not meaningful. Because of this, all the children in the project thought it was best to use monocular telescopes at the same time as the other eye was not occluded or closed. The binocular are held in the right hand if the left eye is used, at the same time as the right eye is open, but disconnected. The right hand "covers" the right eye, and thus helps the use of the left eye.

These are observations which could surely be complemented with other experiences with individual patients, as everyone is unique. But if you consider these

recommendations as general, then they can serve as starting points and reminders in the work with adjustment and training.

Photophobia and nystagmus

One thing that is very important to consider, is the amount of light that the patient handles the best. To be sure, you can also check if they are sensitive to different wave lengths. For example, that they achieve optimal vision with just “the good light” between 500 and 700 Nanometres in the light spectrum. By using the right filter (450, 511, 527, and 550) and complementing the best filter with the right polarizing filter, you can try to bring up the functional vision to a higher and much more efficient level.

Magnification adjusted and related to the needs

In order to see something which is perceived as too small, one has to magnify it. The magnification is usually achieved through relative distance magnification and as an adult you need accommodating devices to be able to see clearly at a shorter distance because of presbyopia. But if you are young you can accommodate, right? Yes, that is true, but another clinical observation is that even though children with nystagmus can accommodate, it leads to increased nystagmus over time since the accommodation usually is combined with convergence. More nystagmus is generated with eye movements, in correlation with attempts to converge, i.e. to look at the same focal point with both eyes.

Therefore it is often recommended to see if a child with relatively good visual acuity and nystagmus would be able to use accommodating devices to facilitate convergence and thus reduce tendencies of increased eye trembling. Even if an improvement is not noticeable at first, you have to check if it brings better endurance and – in combination with the best gaze position – higher reading speed.

The rules for magnification do not apply in this context. It is generally acknowledged, that adults should be provided with magnification so that the best corrected visual acuity (BCVA) at a distance is at least 0.5. A person with VA 0.1 would then need 5X magnification and a person with 0.2 would need +10 dioptres in their reading glasses or 2.5X magnification. However, the principle when it comes to children is to provide half of these magnification levels. If this applies to people with nystagmus, who need help with accommodation, needs to be tested in each individual case.

Using one eye at a time can give more endurance

Another technique which often provides good results, is to make use of the fact nystagmus hardly ever have binocular vision. This means that they can start reading

with the right eye and when they get tired they swap to the other eye. A lot of people use this form of “alternating tropi, which provides the ability to read more pages and for a longer period of time without getting tired too quickly.

Fast head movements when focusing

You often see people with nystagmus move their head with very fast shivering or trembling movements when they try to look at something extra clearly, fixate or focus at a distance or up close. It is easy to assume that the head movements compensate for the eye movements, but that is probably an incorrect conclusion. Firstly, it is not possible to move the head as quickly as the eyes. (To be as quick as “the blink of an eye” means that eye movements are a lot quicker than a lot of other movements.) There is no “connection” found in any of the registrations of eye and head movement either.

The truth is rather that you try to achieve some kind of balance – by moving the head you will not fully compensate for the eye movements, but you do stabilize the gaze and it “feels better”, as a patient described it. If it did not feel better then it would not be such a general and well spread method among persons with nystagmus. Thus, it demands full respect and one should not change or force anyone to give up this stabilizing method in order to “control their perception” while focusing.

If these viewpoints and proposals could provide better reading ability, reading comprehension and visual comfort during reading, then at least we have achieved that. If they could also be an opening to more studies of this group of patients within low vision rehabilitation, then it is yet another move forward in the development of new and documented knowledge.

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