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www.nystagmus.co.uk***



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➔ Welcome to the World of Nystagmus



Hi, I am James and I suffer from nystagmus like thousands of other people. I am currently at high school and about to take my GCSEs. Nystagmus affects me all the time, but I am fortunate because my nystagmus is not as severe as some. I was diagnosed with nystagmus before I was a year old, and my parents never understood how it affected me until I was old enough to describe what I saw.

I decided that I would build a website and document some of my experiences of nystagmus and any information I can find on the subject. It is my hope that I can enlighten parents, friends and teachers of other children as to how nystagmus affects the life of

sufferers.

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I hope that you will find this information and my experiences very interesting to read and that they help you to advance your own understanding of nystagmus. Whether you are a child or adult that has nystagmus, a parent, teacher, or friend of someone who suffers from nystagmus, you will be able to increase your knowledge and hopefully understanding of the problems that sufferers face.

The website is now thriving and is undergoing a revamp, which will hopefully improve the website and make you feel confident in navigating it.

➔ More About Me

I am currently at high school and I have begun the preparation for my GCSE exams. I have nystagmus and have had it since I was born, so I know no different. I have found it difficult throughout my life so far, however I have got used to it and I have overcome most problems that have been presented. I have found it hard to make friends because they have not understood my situation and I have had to work hard at school to try and make my teachers understand.

However I would just like to make it clear that I have found ways around all the problems that have occurred at school, and as a result this disability does not seem to affect me much; I am currently achieving mostly 'A's in all my subjects.

I thought I would write about some of my experiences and provide information for those who are interested in learning about nystagmus. I feel there is a lack of information about the subject and I felt that others wondering about nystagmus may find my own experiences valuable. My parents said that they never really knew what it was like for me until I was old enough to describe it to them. It would have been helpful if my parents were able to understand my problems better, when I was younger, e.g. when trying to ride a bike. Parents may therefore find my information and experiences helpful and enable them to understand a child with nystagmus and to plan for the future.

I feel that children with nystagmus may find this interesting and they may be able to get in contact with others who suffer from nystagmus. Teachers may even wish to find out more information about nystagmus and read about my own experiences at school, in order to make education more accessible to their pupils.

For whatever reason you are looking at this site, I hope you get all the information you want from it.

➔ Scientific Information

➔ What is Nystagmus?

Nystagmus is an involuntary movement of the eyes which is usually from side to side, however sometimes the eyes move up and down and in some cases the eyes may move in a circular motion. The majority of those with Nystagmus have vision which is significantly worse than average and well below what is considered to be short sighted.

Many people can register as partially sighted and a minute number can be registered as blind. Nystagmus is not contagious or infectious. Nystagmus is not painful and it does not lead to total blindness. Vision seems to improve until it stabilises around the age of five or six.

➔ How Common is the Condition?

I understand that nystagmus roughly affects 1 in every 1,000 people.

➔ What Types of Nystagmus are there?

Nystagmus in early childhood may possibly be caused by a defect in the eye or visual pathway from the eye to the brain (the optic nerve). It occurs in a great range of eye disorders during childhood such as cataract, glaucoma, some disorders of the retina and albinism. Nystagmus may also occur in children who have multiple disabilities such as Down's syndrome.

Several types of nystagmus can be inherited. To discover the chances of someone passing on nystagmus to the next generation a specialist must first make an accurate diagnosis of the underlying condition. It may then become necessary to consult a geneticist for detailed information and counselling.

Acquired nystagmus which occurs later on in life may be a symptom of another condition such as a stroke, multiple sclerosis or even a blow on the head. There are many other causes of nystagmus.

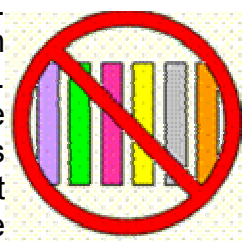
Nystagmus could be a sign of a more serious disorder of the eye or brain. Due to this fact it is vital that when nystagmus first develops in a child or adult they should be referred to an ophthalmologist (eye specialist) or a neurologist.

➔ Experiences At School

➔ Blackboards, Whiteboards and Overhead Projectors

At school the most frequent difficulties arise when copying information and diagrams from black boards, white boards and from over head projectors. Therefore it is of utmost importance that the teacher allows the pupil to sit at the front of the class, as this will help him or her to see what is on the board and increase their chances of copying correctly.

If at all possible it helps if the pupil can be supplied with a hard copy of what they must copy so that they can place it appropriately to maximize their vision of it. If this cannot be done the teacher should write big, bold and clearly on the board as it can be hard to decipher joined up writing that is small. People with Nystagmus often find it difficult to see various colours (see diagram to the right) so if you come into contact with someone who has Nystagmus try to avoid using these colours. However this does not apply to all colours (black and blue are easily seen by myself), so use



these colours if at all possible.

It may sometimes be necessary for the teacher to read out what they have written, so it is a good idea to read out what you are writing anyway. In my opinion, the teacher should ask the pupil if they are having any troubles, because they may not want to tell them!

→ Bullying

At school I was called names by many people until they either got tired of me not responding or until they understood Nystagmus. One of the most common phrases I heard was 'wibbly-wobbly eyes'. I just ignored them and eventually they went away. Lots of people also called me 'four eyes' but that is just as common as muck and most people that wore glasses were called this. Even now the occasional person calls me 'four eyes' but most of the people at school seem to have more sense now. As I told more and more people about my eye condition I gained supporters who would stick up for me if anyone else started to call me names. Therefore the names just gradually faded out. For example at middle school I had terrible trouble with people calling me names, and there was one person who supported me through this period (Lee). He even lost friends because of it. So thanks Lee. There is always an end, and I have never experienced a bad ending. If people call you names, just ignore them and do not try to be friends with them; it won't work. You will always find someone to be your friend!

→ Consecutive Capitals

I, and I assume most other people who have Nystagmus, find it hard to read consecutive capitals. So please try avoiding it if at all possible. For example...

THIS IS HARD FOR ME TO READ!

→ Exams

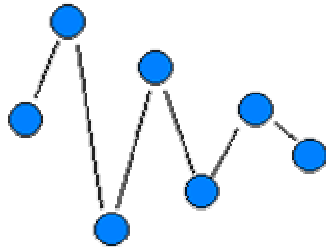
For my year 9 SATs I was given extra time, and I have been allowed extra time ever since. I am allowed to have 25% extra time in my exams, this will also be true for my GCSE exams over the next couple of years. This has been very useful as I read slower than normal because of Nystagmus. If you are worried about your exams I would go and see the Exam Officer or the Special Needs Co-ordinator at your school.

If you suffer from nystagmus and live in the UK, you are entitled to extra time for most public exams to the order of 25%. These include GCSEs, AS and A2 level exams. For more information contact your education establishment's exam officer.

I am going to benefit from this 25% extra time for my GCSEs coming up this year.

The full rules and regulations are available from the Joint Council for General Qualifications at [http://www.jcgg.co.uk/Publications and Common Docs/Regs & Guidance.pdf](http://www.jcgg.co.uk/Publications_and_Common_Docs/Regs_&_Guidance.pdf).

Physical Education



I find various elements of PE difficult as a result of Nystagmus. These are mostly activities that involve a ball. When a ball is coming towards me it appears to move from side to side and as it gets closer it does not seem to move as far from side to side. So I attempt to judge the centre of its path when I play any ball game where I have to hit the ball. This procedure works well for me as I seem to be able to gauge the centre of the balls path quite well.

I don't just find ball games hard but also athletics like running as I often find it difficult to stay within my lane because the lines of the lane appear to be moving.

I also find it very challenging climbing the apparatus because when I take a foot or hand off a bar, the bar I go to put it on is moving, so I have to guess where it actually is. When this does happen it can become scary and make me even more nervous causing my eyes to move even faster.

My balance also seems to be affected as I find it immensely hard to walk along a beam without falling off.

I do however play squash during PE at school quite successfully, which just goes to show that sport is not impossible, though I will probably never be brilliant at it!

Reading

People with Nystagmus are often fairly slow readers, but they can still read. However they may become tired more easily than most, depending on the size of the writing.

I can manage to read very small writing but I get tired quickly.

I can manage to read very small writing but I get tired quickly.

I can manage to read very small writing but I get tired quickly.

I can manage to read very small writing but I get tired quickly.

I can manage to read very small writing but I get tired quickly.

I can read the smallest writing in the box above but it takes me about twice as long to read it than the biggest writing in the box above. Although I am slightly slower than everyone else I manage.

I have to hold a book very close to my eyes when reading as it is more comfortable and makes it easier for me to read. Everyone with Nystagmus has a point where their eyes stop moving. You can discover this point by holding out your index finger at arms length, and gradually move it closer to you while continually concentrating on it. Make sure

someone is watching, they can tell you when your eyes stop moving. It is at this point that things become in focus, and this is where I hold a book when reading. I cannot focus when my eyes are moving constantly.

➔ Sharing

It is almost impossible to share a book or worksheet with another pupil because it will most probably not be in a place where we both can see it, especially for the pupil that suffers from Nystagmus. There shouldn't be too much trouble as long as the pupil can have access to a book or sheet for themselves, and of course the teacher understands.

I find it difficult to work on a computer with another pupil, because I need to sit close to the screen in order to read the text there and to operate it. Lots of people comment on how close I position myself to the monitor.

In a similar way at home I need to sit close to the television in order to see it clearly. My parents were told that they should let me sit close when I was still at an early age. I have a special chair in our lounge positioned close and to the side of the television, but not obscuring the screen from other viewers. I also now have a television in my bedroom for convenience.

➔ The Speech

When I was 10 I wrote a short speech which I read to the rest of my class at school because I had many, many people who were, shall I say curious about my eyes and they wanted to know why they moved like they did. They kept on bugging me and so I wrote this:

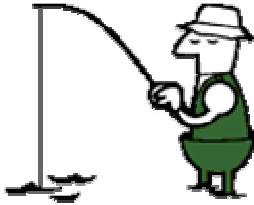
"As you have probably noticed my eyes move from side to side most of the time. This is because of a rare eye condition called Nystagmus, which means I am unable to control the muscles either side of my eyes. Unfortunately when my eyes are moving I do not see clearly, for example when I see a ball coming towards me, it is travelling in a zig-zag. So I find rounders and games like that, hard to play, and think I'll let the team down. I have had to give up my bike because I can't ride it in a straight line and it could become dangerous. I find climbing on the apparatus difficult too, because when I take my feet or hands off and am about to put my foot on a different bar, the bar moves, so it is hard to determine where to put my foot or hand. I need to sit close to the blackboard and the TV, to see them clearly. When I am reading I need to hold the book close to my eyes. My eyes do not move so much when I am concentrating on a near object. I can show you...

(At this stage I showed the class how my eyes will stop or slow. I did this by holding my index finger out and I gradually moved it closer to my eyes and as I concentrated on it and it got closer my eyes gradually slowed at a certain point!)

...It is often difficult living with Nystagmus. Especially when I am teased. I will always have Nystagmus because so far, doctors haven't discovered a cure."

➔ Personal Experiences

➔ Fishing



I go fishing on a fairly regular basis and enjoy it very much, however there are various aspects of fishing that I find difficult because I have nystagmus. One of the main problems I experience is tying knots so I now buy as many of the main components already tied. For example I now purchase hooks that are already tied to nylon. I often tie any knots very large as I find it easier to manage with. I also have difficulties when float fishing especially when it is very windy because it creates ripples and the water reflects the sunlight into my eyes. I have just recently bought some polarised glasses which should relieve the problem. I usually fish on the bottom using bite alarms because I do not have to constantly observe a float which can strain my eyes and all I have to do I listen out for the alarm.

➔ Music

I can play the piano and saxophone and because of this I have come across several problems that are a result of having Nystagmus. Firstly I can find it difficult to read music if the notes are placed closely together or if the music is relatively small. I find music with the notes well spaced, rather than bunched together easier to read. I have also had difficulties in the past with music stands because I need the music close to me. If I am standing up I require the stand to be almost at face level so I can read the music. I really find it almost impossible to share a music stand because it usually means that the stand ends up too far away from my eyes.

➔ Paper Rounds

When I first started a paper round I found it difficult to read the house numbers from the road especially if the house was set back from the road or if the number was small. Because of this, I went round beforehand, which helped me to remember where each house was.

➔ Recognising People

Wherever I am I have trouble recognising people that are a certain distance away. I have to actually cross the road when I hear someone call my name otherwise, I would have to rely on voice recognition. This can be very frustrating, especially if it is someone I do not at all want to talk to. On the other hand there have been times when I have chosen to ignore a voice that I didn't recognise, and this has been inappropriate too. If I go to town or to a large shop with my parents I make a mental note of what they are wearing and I go by this when attempting to locate them - it usually works.

➔ Riding a Bike

I think that my dad must have thought that I was just lazy because I hardly ever rode my first bike, when any other child would have been in trouble for not stopping! My parents spent hours trying to teach me to ride a bike, but it took me a long, long time. I still had stabilisers on at a late stage too because my balance was not very good. Eventually I managed without them but I still found it difficult. One of the troubles that I had was that I could not ride in a straight line very well. This was due to the fact that as my eyes moved from left to right continuously, the curb appeared to move in the same way. I always used to try and ride close to the curb and in a straight line, but it was very difficult for me. My parents would not let me go far, and were concerned even when they rode out with me. There was a stage when we sold my bike because of this problem, however we later got another one because I wanted to try again. This time I did not rely as much on the curb but instead I just guessed, and amazingly it seems to have worked a treat. I still have a bike now and I haven't fallen off or lost my balance for ages. However, I am told that I ride out into the middle of the road to pass parked cars. This is because they move, with my eye movement, as I approach them.

➔ Prospects – The Future

➔ Driving

I realise more than ever that it is almost certain I will not be able to drive. I believe that one of the criteria is that you have to be capable of reading a car number plate 20.5 metres away - I can barely manage to read one 10 metres away! I also have great difficulty in reading road signs when in a moving vehicle. There is a point where I can read the signs, but it is only from about two metres, I'd have to park underneath it! Even if I did manage to pass a driving test I do not believe I would be comfortable driving in these circumstances.

For more information about your eyesight related to driving visit the Driving Standards Agency (UK) (<http://www.dsa.gov.uk/>) website, in particular the page about 'Eyesight Requirements' under the 'Learners' section of their website (http://www.bsm.co.uk/learning_to_drive/2.html).

Because I will almost certainly not drive I have to think about what sort of job I would look for, and the location of it. Obviously, one easily accessible by public transport would be ideal. However if you are registered as partially blind you will receive free or reduced bus and train fares, which would be a benefit.

➔ Getting a Job

In the future when applying for a job I have to decide whether or not to divulge the fact that I have Nystagmus. If I did, they may decide that they don't even want to interview me because I have this condition. However if I don't tell them about it, problems may

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arise whereby, I am unable to do a particular task. So I will have to decide whether I tell my possible employers that I have Nystagmus.

I think that being self employed would be the best thing as I would be my own boss and I could control exactly what I do.

Disclaimer

All information found on www.nystagmus.co.uk or in this document is not necessarily fact, it is a combination of fact, opinion and personal experiences. Everyone with nystagmus is affected differently and experiences mentioned may not apply to everyone, and if they do, other people might not be affected as badly. Please do not read all this information and use it to stereotype people with nystagmus as everyone is affected differently.

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