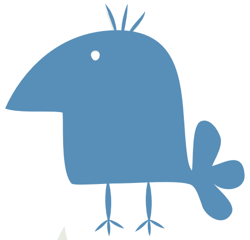
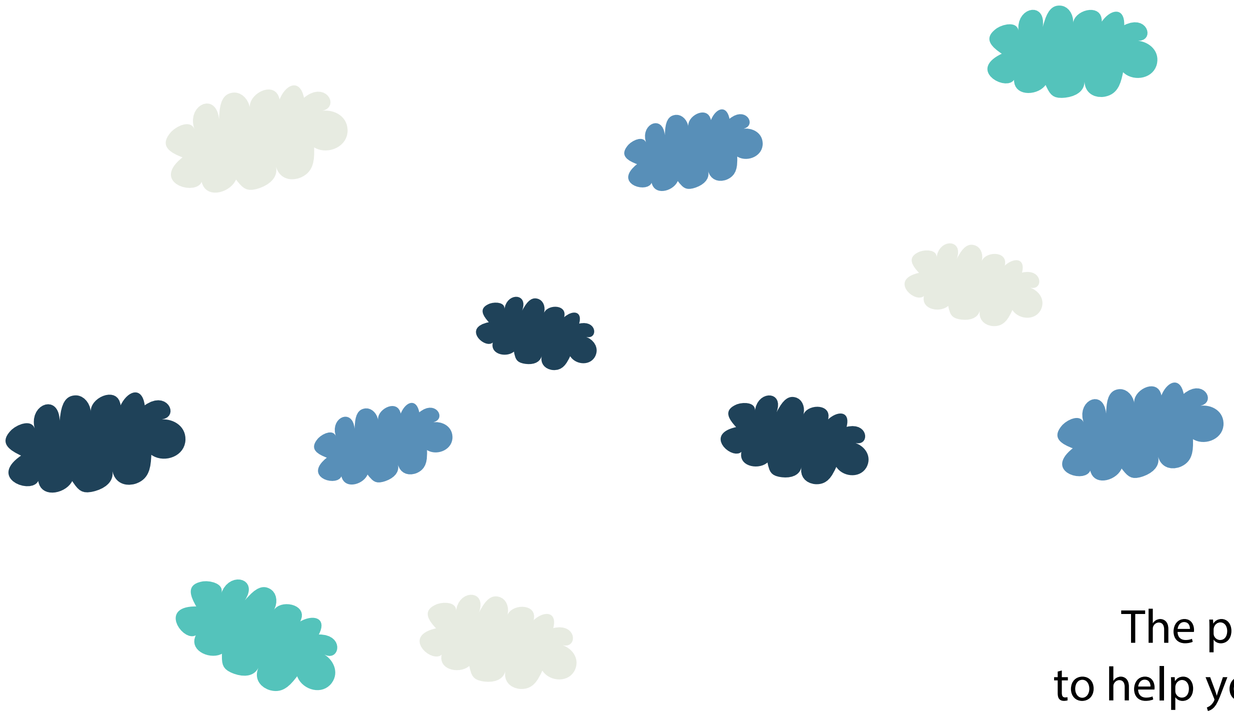
Nystagmus Network

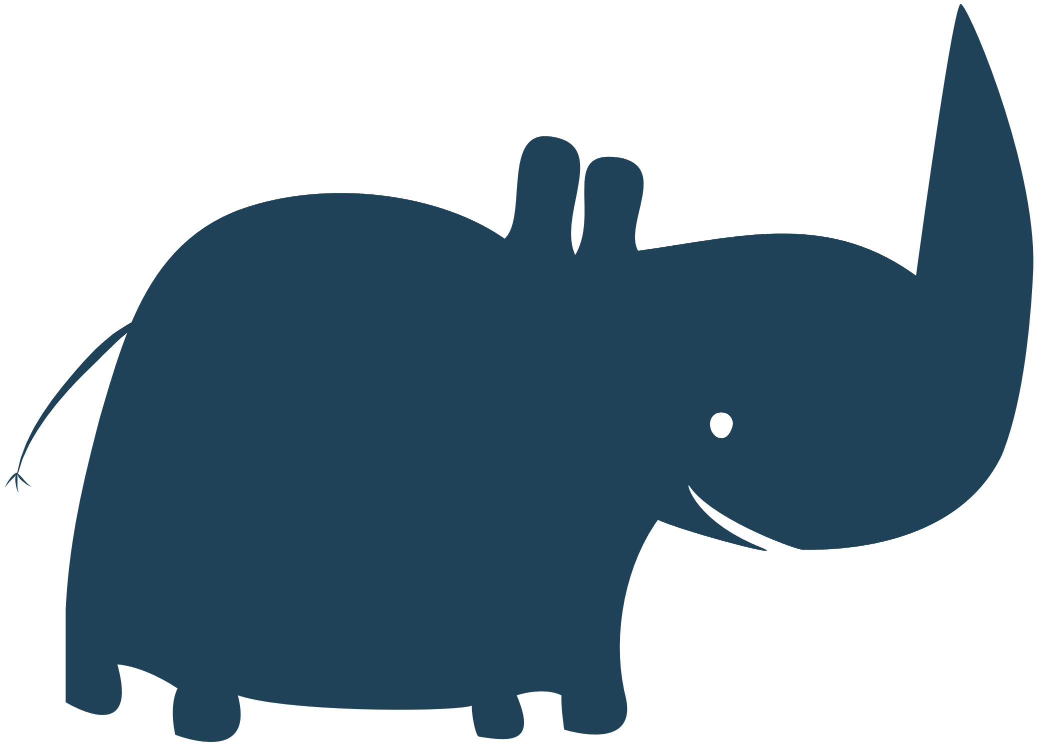
The Nystagmus Network is a registered charity in England and Wales - 803440

Wobbly Eyes





Introduction



The purpose of this booklet is to help you explain nystagmus to a child. When the child is confident enough, they will be able to share the booklet with their friends.

When and how you tell a child they have a visual impairment is a very personal decision. Only you will know when the time is right.

Take your cue from the child. They will probably work out fairly soon that not everyone has to go to the eye doctor so often or get their eyes tested all the time. If you start the conversation early the child is less likely to worry that there is something seriously wrong. They will also get into the habit of talking about their sight.

This will pay dividends later on when they need to ask for support at school or explain to their friends why they are just a little bit different.

Make sure it's a time when you are feeling relaxed about the child's nystagmus. You will need to have come to terms with it yourself before you can help a child do the same. And whatever you do, don't fuss! Teenagers tell us all the time that they didn't want their parents to wrap them in cotton wool when they were little!

Here are just a few suggestions on how to tackle this sensitive subject and the answers to some of the questions a child may ask about nystagmus.

What's wrong with my eyes?

When you were a little baby doctors noticed that you had nystagmus. This means that your eyes keep moving all the time instead of staying still like other people's. This is nothing to worry about but you need to know that you may not be able to see quite as well as everyone else.

It's hard for you to understand how nystagmus affects your sight. You won't be able to compare your vision so you won't know how well other people can see. They might ask you if you can see things but they still won't know exactly how much you can see. Only you know that!

You might be able to see things really well when they're very close to your eyes, but find it harder to see things further away from you. Remember everyone is different, including their eyes and no two people with nystagmus see exactly the same as one another.

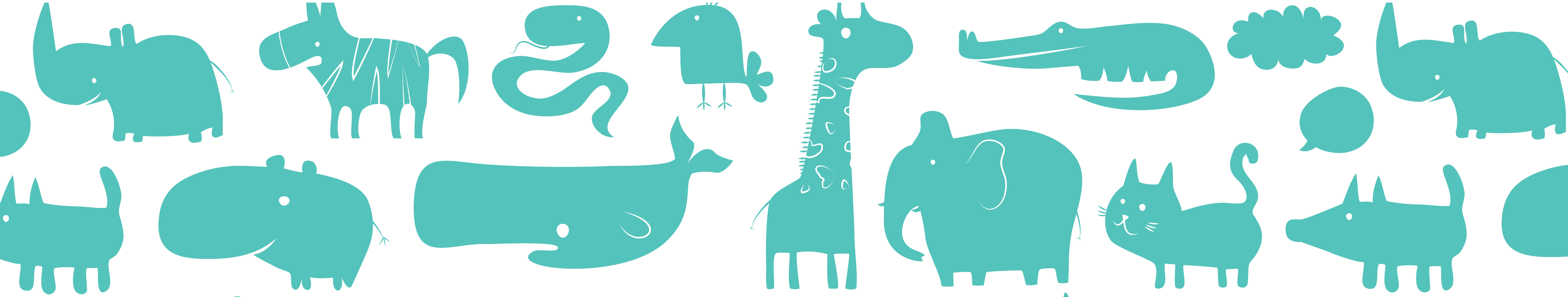
Will my eyes get better?

Everyone who has nystagmus wants to know if it hurts, will it get better and will it stop them from living their dreams.

Nystagmus doesn't hurt. You won't be able to feel your eyes moving. You probably can't even see them moving in a mirror. Why not have a look! Glasses can't stop your eyes from moving, but they can help you see better, so lots of children with nystagmus wear glasses.

You will always have nystagmus and unfortunately it won't go away. You will learn to live with it like lots of other people. You've probably noticed that you have to go and see an eye doctor quite a lot. That's to make sure that your eyes work the best they possibly can.

You might already have glasses to help you see. This doesn't mean that your sight is getting worse. In fact it might get a bit better as you get older. However, it is important that you use all the visual aids available to you so that nystagmus does not hold you back.



At home with nystagmus

To help you get around without bumping into things, you probably try to remember where things are. This is really useful as long as things don't get moved around suddenly. You'll probably prefer things to be quite tidy around the house so that you don't trip over too much. You'll need to be a bit careful on stairs. This is because your nystagmus means that you can't always tell how high steps are or exactly where they begin and end. With practice you'll soon get used to it.

Because you can't always see things that are quite far away, it's a good idea to have a book or screen close to your eyes or sit close to the TV. This won't hurt your eyes but it will help you to see better. The rest of the family might not like it that you always sit in front of them but they need to understand that you need to do this to be able to see the screen.

Some people with nystagmus have something called a null point. This is a position you can turn your head in where your eye wobbles slow right down. So of course it means that you can see more clearly. Don't worry about trying to find your null point. You probably found it when you were a tiny baby just learning to sit up and you've been using it without even realising it ever since. The only way you will know if you have a null point is if you ask someone or if you notice that you always prefer to sit on one side or the other to share a book, or a computer screen or to watch TV.

"Nystagmus
has never held
me back from
living my
dreams."

Going to school with nystagmus.

At school it will help a lot if you and your parents explain to your teachers how nystagmus affects your sight. Then they can help you to find a place in the classroom where you can see the board.

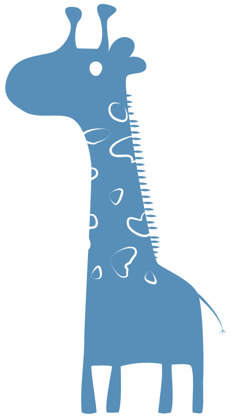
You might get your own laptop, iPad or tablet, so that you can see clearly what everyone else sees on the board. You can adjust the screen and open and close one or two things at a time so that your screen doesn't get too full or jumbled.

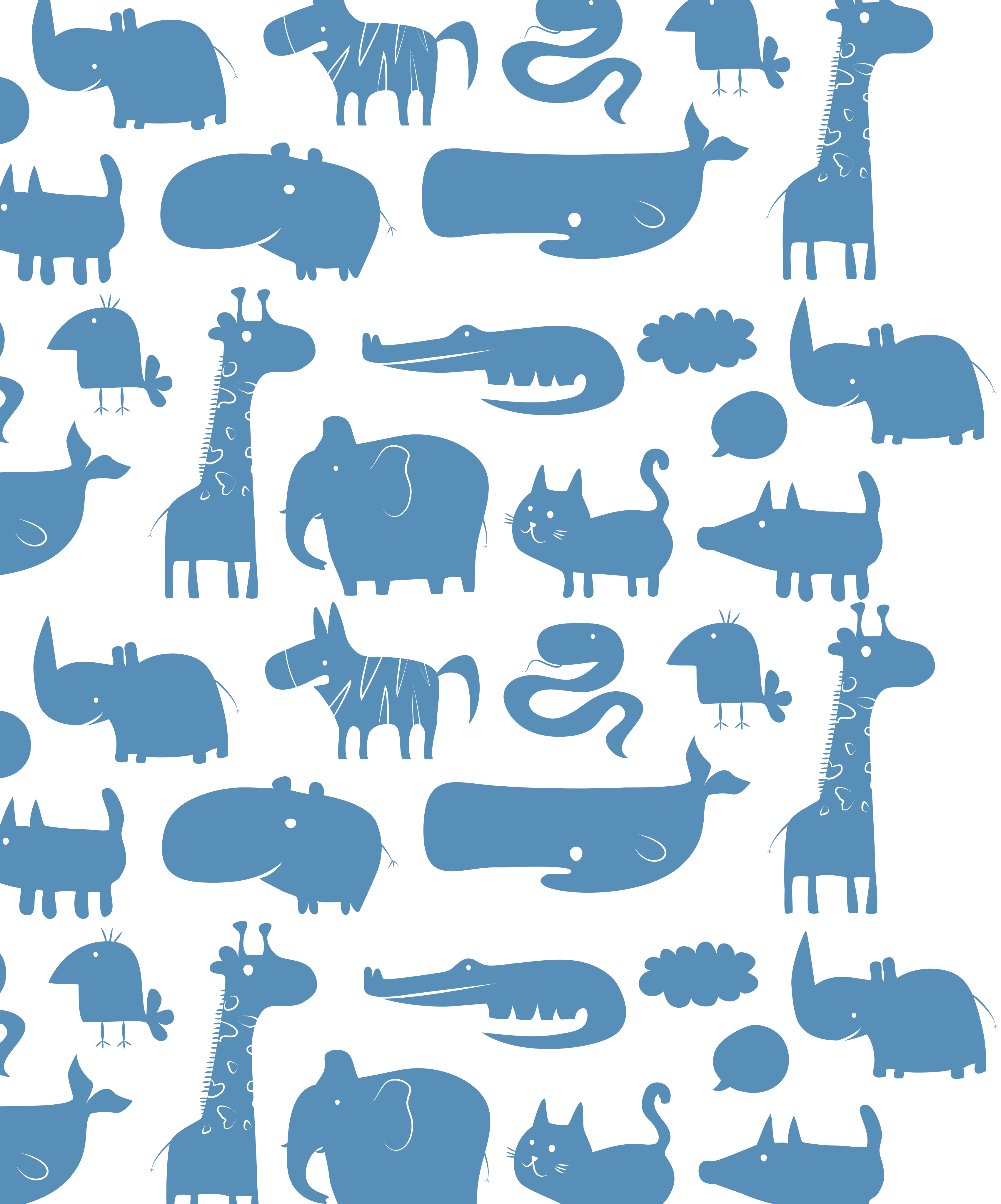
It's easier for you to find books, pens and other equipment you need if they're labelled with a brightly coloured or tactile sticker. At primary school this is important for clothes pegs, PE bags and clips for your wellies as well.

When you’re reading books at school or at home you might find it hard to share a book, because you won't be able to get close enough to see the writing. You’ll also need to work out what size of print you can see comfortably. You might be able to use magnifiers to help you read books, or use a slotted card or ruler so you can see just one line of the story at a time. On an e-reader or computer screen you’ll be able to alter the text size, contrast and background colour for yourself. If your teacher gives you worksheets to do, you’ll need to say what size of print you need and perhaps try different colours of paper, too, to find out which one is most comfortable for your eyes. Ask for your work to be adapted and copied on to A4 size paper, not A3. That's too big to work with.

You might struggle with handwriting a bit and prefer to take notes on an iPad. But there will be times when you need to write things down so that you or somebody else can read what you’ve written, so you’ll need to keep practising your handwriting. You might want to learn how to touch type so that you can type more quickly. Your teachers will be able to help you with this. If you find it takes you a bit longer than everyone else to get things finished, it’s not a problem. Your teacher will make sure you have plenty of time to get things done and still be able to go out at break and play with your friends.

Remember – if you need help, just ask.





Out and about with nystagmus

Sometimes nystagmus can make you extra sensitive to bright lights. You might notice that your eyes feel uncomfortable on really sunny days. Wearing sun glasses or a baseball cap can help with this.

Some ball games can be a bit tricky for children with nystagmus, because it takes you longer to see where the ball is and you don't have time to catch it. Don't let this put you off trying different games. Swimming, running and long jump are no problem for someone with nystagmus and there are lots of Paralympians who have it.

Making friends as you grow up...

...it's easy if you tell them about your nystagmus!!!

It's important to make friends, especially at school, but it can be a little bit difficult when you can't see very well. You might not always be able to tell when someone is looking at you or whether they're happy or sad if you can't see their face clearly. Make sure your friends know about your nystagmus. They can help you by looking at you when they're talking to you and standing nice and close.

In the school playground when everyone is running around or wearing the same colour school uniform it can be a bit scary trying to find your friends. You could try asking your friends to call you or wave at you when you see them so that you can see where they are. They won't mind because they're your friends.

Because nystagmus makes your eyes wobble and because it might make you turn your head to the side, this could make you look a little bit different. Lots of people won't even notice and certainly won't say anything rude about it. But you need to know that some children can be a bit horrible if they don't understand something. They might call you names or laugh. This isn't very nice so you need to explain about your eyes, that you can't help it, so that they understand. If they still call you names or don't want to be your friend, talk to your parents or a teacher about it.

If you feel brave enough you might decide to do a presentation about nystagmus for your class in form time. Then everyone will understand about nystagmus. Remember to tell everyone that nystagmus isn't catching! All the other children could do a presentation about what's special about them.

Shape your own future

You can achieve everything you want with hard work.

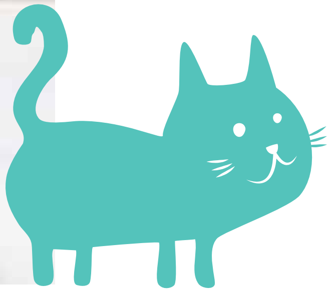
People with nystagmus grow up just like everyone else. They can choose which university to go to, what job to do, whether to get married and have children, just like everyone else. There are lots of successful athletes who have nystagmus. There are also scientists, doctors, teachers and even television presenters.

Having nystagmus simply means you can't see as well as some people. At school you need to try your hardest and make sure you get all the help you need to get the best possible exam results you can. Having nystagmus doesn't mean that you can't do anything you want to do. Don't let it hold you back.

This booklet was written by the people at the Nystagmus Network, which is a charity to help people with nystagmus and their families. We can help you and your family meet up with other people who have nystagmus and share your stories then you'll know you're not the only one. We will always be here to offer you support and advice throughout your life.

“I’ve always loved stories, but because of my nystagmus I struggled to read when I first started school. Now I’ve got a degree in philosophy."

“My nystagmus never really caused me any problems but when I started school lots of people started asking me why my eyes were moving."



The Nystagmus Network relies entirely on membership subscriptions, fundraising and donations to continue its important work, providing support and information to the nystagmus community, raising awareness and funding research.

If you have found this free document useful, please consider making a donation to the charity today. Thank you.

nystagmusnetwork.org