



Nystagmus *Network*®

Supporting a child with nystagmus

The Nystagmus Network is a registered charity
in England and Wales, number 1180450.
To make a donation, please visit [CAF Donate](#).
Thank you

A young child's sight continues to develop and improve throughout the early years. It's important to understand this and stimulate their curiosity in the world around them.

The Nystagmus Network is here to provide support and information.

Copyright © 2021 by Nystagmus Network
All rights reserved. This document or any portion thereof may not be reproduced or used in any manner whatsoever without the express written permission of the publisher.

Introduction

This booklet provides guidance for parents on how to support a young child with nystagmus at home.

The Nystagmus Network is a UK registered charity providing support and information about the eye condition, nystagmus. The charity was established in 1984. We support people living with nystagmus and also promote a better understanding of the condition. Through the charity's extensive involvement in research we are moving closer to finding effective treatments.

This booklet is for parents and carers of children with nystagmus. It is just one in a series of publications by the Nystagmus Network to help you become better informed about your child's condition. This booklet focuses on how to support a young child with nystagmus. The other documents cover education and driving. Reading these documents will ensure that you are equipped to support a child with impaired vision and that your child, even though they have nystagmus, will meet all their milestones and achieve their potential at school.

How can I contact the Nystagmus Network?"

Email: info@nystagmusnet.org

Phone: 01427 718093

Post: 70 Hyde Vale London SE10 8HP

Web: www.nystagmusnetwork.org

Visit the Nystagmus Network Facebook page for all the up to date news and stories about nystagmus. To chat with other parents of children with nystagmus, why not join our Facebook parents' group?

Please also see our Teachers Booklet and 'Wobbly Eyes', our booklet explaining nystagmus, especially for young children.



How can I encourage my child to see?

There is lots a parent can do at home to stimulate a child's sight

If a child is not diagnosed with nystagmus shortly after birth, it is often noticed at home at around 6 weeks of age. Your baby may not be able to follow a toy moving slowly in front of their face or make eye contact with you during feeding. You can help your child learn to focus, by keeping your face close to theirs and exaggerating your facial expressions when you talk to them during feeding, changing and bathing. They may not be able to recognise your face just yet, but they will learn to know your voice and associate the sound with what they see.

Nystagmus can affect a child's vision in different ways. Most children will not be able to see very far. Once your child is sitting up they may not be able to see you when you walk across the room, but if you talk to them whilst you're moving they will learn to follow your voice.

They may be able to see things when they are very close to their eyes, so show them toys and let them hold them and inspect them closely so that they can see and feel the detail. Offer them brightly coloured toys, with different shapes, sizes, textures, switches and sounds. Once they can recognise their favourite toys, you can encourage them to explore, by placing their toys just out of reach.

Let your child explore their world. Teenagers with nystagmus tell us all the time they never wanted to be wrapped in bubble wrap!

Start reading books to your child very early on and let them hold them close to enjoy the colours and pictures. Books with sounds, flaps to lift and textures are particularly stimulating.



How well can my child see?

Recent research now enables clinicians to predict, with some accuracy, how well a baby will be able to see when they are older.

No two cases of nystagmus are ever quite the same, but you will soon notice that your baby can see things when they are very close to their eyes. This distance will gradually lengthen as they grow older, but they may not be able to see things further away clearly.

Although you might imagine that they see things moving around, this is not usually the case. A baby's brain adapts to the eye movements and produces a still image of the world most of the time.

A child with nystagmus may find it difficult to pick out an object in a group. Place their favourite toy slightly apart from the rest so they can find it.

Your toddler may continue to struggle to follow faster moving objects such as balls. This is because nystagmus can affect the ability to see in three dimensions and to judge distance and speed.

Once they are walking, you may notice that steps and even changes in the colour or texture of the flooring make your toddler hesitate. This is because they cannot necessarily see that the floor is flat or that a step is there.

If you move things around at home, your child, who relies quite a lot on memory, may become confused and bump into things they were not expecting to be there.

You may find that your child's vision changes throughout the day. It may get temporarily worse, for example, if they are tired, anxious, unwell, hungry, stressed or excited. Parents may notice the amount of 'wobble' increases, too, at certain times of the day.

They may also be sensitive to strong light, both artificial light and sunlight, becoming dazzled and finding it very uncomfortable.



How can I support my child at home?

There are lots of things a parent can do at home to help a child with nystagmus make the most of their vision.

- Find as many ways as you can to stimulate your child's **curiosity** in the world around them.
- If they need **glasses**, make sure that they wear them.
- Even completing **everyday tasks** with your child, like baking or washing, can stimulate the sight.
- **Low Vision Aids** – As well as glasses and contact lenses, there are lots of magnifiers to try. Visit a **Low Vision Clinic** to let them try out different devices and hand held technology.
- **Adapting a computer screen** – Help your child try different colours and contrasts on a computer screen as well as enlarging text and images. If they are sensitive to bright light, toning down the contrast can reduce eye strain.
- **Large print books** – Kindles and similar devices can help your child access books and stories easily. Large print versions of story and school books are available to order from CustomEyes by Guide Dogs.

Children reach their milestones at different times, whether or not they have nystagmus.

Some children with nystagmus are reluctant to walk, whilst others seem totally fearless and not at all worried about bumping into things.

With your gentle encouragement, your child will do everything as soon as they are ready - even riding a bike.

“Why does my child have different issues with their sight from their friends who have nystagmus?”

Every child is unique and nystagmus will vary in its effects from one to another. Quality and clarity of vision is not necessarily related to the amount, speed or type of eye movement. The nystagmus itself will vary according to the time of day, the brightness of the light, how the child is feeling as well as other factors.

What is the impact of nystagmus?

Nystagmus can affect more than just the sight. There may also be some social or emotional issues.

Children with nystagmus sometimes look a little different from their peers. From a distance it may be difficult to tell, but if the child has a head turn or tends to nod or shake their head, this will be noticed and, close up, it may be possible for others to see the eyes wobbling. A child may not be aware of any of these differences and most likely cannot see their own eyes wobbling in a mirror or video.

Talk to other parents or the school to pre-empt any potential teasing.

If your child is struggling to make friends at school, you can talk to the staff about buddy schemes, designed to help children make friends or join new friendship groups, or arrange play dates with other families.

Your child can overcome any potentially awkward situations themselves by simply explaining about the condition. Give them the confidence to tell you or their teachers if there is a problem so that it does not escalate. A successful intervention may include a child giving a presentation to their class on Nystagmus Awareness Day so that their peers can gain a deeper understanding of the condition and have all their questions answered. It is common for problems with teasing or bullying to stop once a child has explained that nystagmus is a medical condition they were born with and that it is not catching!

“When I discovered my daughter was being teased due to her nystagmus, I was devastated. The school was amazing at offering us support and making sure she didn’t feel isolated as a result.”



Out and about

Nystagmus also impacts children outside the classroom. They may struggle to recognise friends in the playground or join in with fast moving games. They may find it difficult to make eye contact with people, read facial expressions or know when someone is talking to them. This can sometimes make them appear unfriendly or shy. An effective strategy is for a child to explain to their friends that they sometimes feel left out of activities they struggle with because of their nystagmus. Make sure that staff, other parents and the children understand this. They will usually be happy to help them join in.

Children with nystagmus commonly need more time to see and take in the world around them. In a busy or cluttered environment such as a play group, for example, it may take a child more time to recognise even familiar faces, find toys to play with and understand about sharing with other children. Give your child time to take in their surroundings and show them where key things are. They will soon learn to memorise these, so it helps not to move things around too often, especially without telling them.

Many parents worry about their children learning to cross the road. For a child with nystagmus this will naturally be a greater concern due to nystagmus compromising depth and speed perception. Lots of practice and support will be needed until a child can manage roads and unfamiliar steps on their own so that they can gain more independence. Ask your local sight support team for help with mobility training.

A child with nystagmus may take longer to ride a bike without stabilisers, but most children manage this in the end.

Older children can have mobility training to help them walk independently to school safely.



Support stories

Each child diagnosed with nystagmus may have a different experience of the support services available to them.



“When I found out my baby had nystagmus all I wanted to do was meet other parents and nystagmus ‘survivors’. I achieved this through the Nystagmus Network.”

“If only I could have known what a confident young woman my daughter would become, I would not have worried so much about her future when she was first diagnosed with nystagmus.”



“From day one I talked to my child about nystagmus. There were no secrets and no big surprises, just lots of understanding and getting on with it together.”



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 through CAFDonate. Thank you.

If you would like to join the Nystagmus Network as a member, you can find out more on our website about the benefits of membership.

Contact the Nystagmus Network

web www.nystagmusnetwork.org

email info@nystagmusnet.org

tel 01427 718093

post 70 Hyde Vale
London SE10 8HP

Linkedin [linkedin.com/nystagmusnetwork](https://www.linkedin.com/company/nystagmusnetwork)

Twitter twitter.com/NystagmusUK

Facebook [facebook.com/NystagmusNetwork](https://www.facebook.com/NystagmusNetwork)

Instagram [instagram/NystagmusNetwork](https://www.instagram.com/NystagmusNetwork)