

Nystagmus Information Pack



Part 1. Introduction: What is
nystagmus?

CONTENTS

The different documents that make up the Nystagmus Information Pack can be downloaded or printed.

The documents include:

1. Introduction: What is nystagmus?
2. Infantile nystagmus
3. Acquired nystagmus
4. What to expect at eye clinic appointments
Terminology explained
5. Treatment options
Long term outcomes
6. Support
Useful contacts and sources of information
7. Example information sheets and example letters



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

ACKNOWLEDGEMENTS

For helping develop this Nystagmus Information Pack, we would like to thank:

- * Nystagmus Network and the University of Sheffield for their funding.
- * The facilitators, families and children at the Nystagmus Network open days 2015 and 2016 for their valuable advice, guidance and recommendations.
- * The individuals with nystagmus and their families who reviewed the pack and made useful suggestions.
- * Members of the British and Irish Orthoptic Society and the orthoptic departments across the UK and Ireland that contributed to the content.
- * The orthoptic students at the University of Sheffield for participating in the Nystagmus Network open days. They listened to and analysed valuable information and suggestions from children and adults with nystagmus and their families.
- * Anwen Coughlan (orthoptist and research assistant) and Arthur Nye (research assistant) for their work on this information pack.
- * Gemma Arblaster, Anne Bjerre and Dr Helen Griffiths, Academic Unit of Ophthalmology and Orthoptics, University of Sheffield.



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

INTRODUCTION

This information pack about nystagmus has been developed for patients, parents and carers.

A diagnosis of nystagmus can be a shock. Each person's diagnosis and vision is individual and nystagmus is caused by many different things and affects individuals differently.

The following guide provides an information overview of what nystagmus is, what life can be like with nystagmus and most importantly the support that is available to you, your children, family, friends and community.

You will have many questions and it is our hope that this guide can answer some of these questions or point you in the right direction to find those answers. Living with nystagmus is a journey, there may be challenges but there are a wealth of adaptations, lots of support, technology and information available to help you fulfil your potential and lead an independent life.



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

WHAT IS NYSTAGMUS?

Nystagmus is characterised by involuntary, repetitive, rhythmical movements of the eyes where they appear to wobble or flicker. The movement can be slow or rapid, side-to-side, up and down or circular. It is usually seen in both eyes but in rare cases, can affect only one eye.

Nystagmus leads to decreased vision and needing more time to try and see things. Due to the constant movement of the eyes, the eyes are not still when a person is trying to look at something. This means the image "slips" from the fovea - the area of the retina at the back of the eye, which provides the best level of vision.

As the eyes are constantly moving, the fovea has brief moments focussed on the image of interest. The brain then uses these brief glances to see, a process that takes longer and is often less clear in those who have nystagmus compared to someone whose eyes are still.

There are two main types of nystagmus, infantile (sometimes called congenital) and acquired. Infantile nystagmus is present at birth or within the first few months of life. One in 1000 children are born with infantile nystagmus, or with a condition that will lead to infantile nystagmus. Acquired nystagmus occurs later in life and is typically associated with neurological disorders or loss of vision.

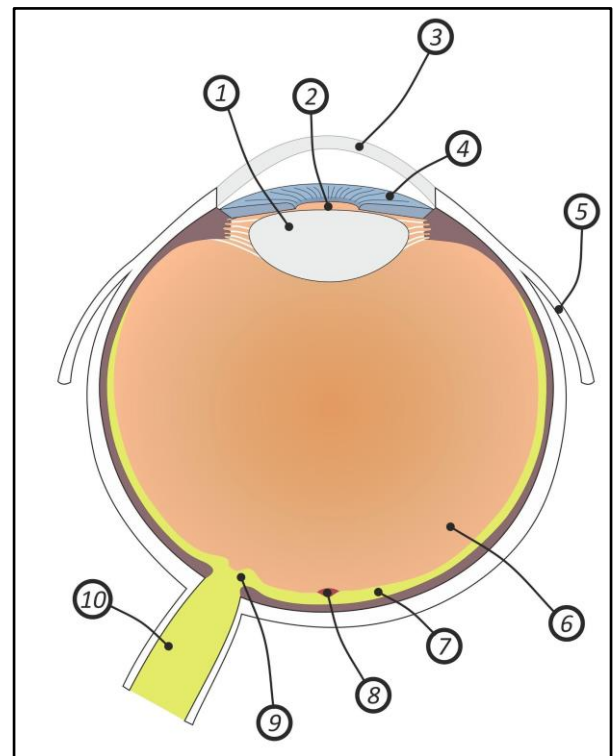


The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

Figure 1. A cross section diagram to show some of the structures within and around the eye.



1. Lens - focuses the image onto the retina (7) and fovea (8) at the back of the eye
2. Pupil - the hole in the middle of the iris (3), which changes size in different lighting conditions
3. Cornea - the clear part at the front of the eye
4. Iris - which is coloured
5. Extraocular muscles - there are six muscles attached to the outside of each eyeball, which move the eyes
6. Vitreous - clear jelly inside the eye
7. Retina - the light sensitive layers of cells at the back of the eye, which are used to detect light
8. Fovea - the small area of the retina (7) that is used for the best vision, as it contains lots of light sensitive cells
9. Optic disc - where the optic nerve (10) connects to the eye
10. Optic nerve - used to transmit visual information from the eye to the part of the brain used for vision



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.