



Nystagmus Network®

1984 - 2024

The Nystagmus Network is here for you!

www.nystagmusnetwork.org

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on Facebook: Nystagmus Network

on Twitter: @NystagmusUK

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What is nystagmus?

Nystagmus is a form of visual impairment, characterised by involuntary eye movements.

At least **1 in 1,000 babies** are born with nystagmus.





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Congenital or Infantile Nystagmus can result from

Eye disorders such as

- childhood cataracts
- optic nerve hypoplasia
- strabismus

Genetic disorders such as

- albinism
- congenital stationary night blindness
- achromatopsia
- aniridia

or it can be “idiopathic” which means ‘cause unknown’



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What's nystagmus like?

Richard Osman
has **nystagmus** and
appears in our video:
**Nystagmus, the
way we see it.**



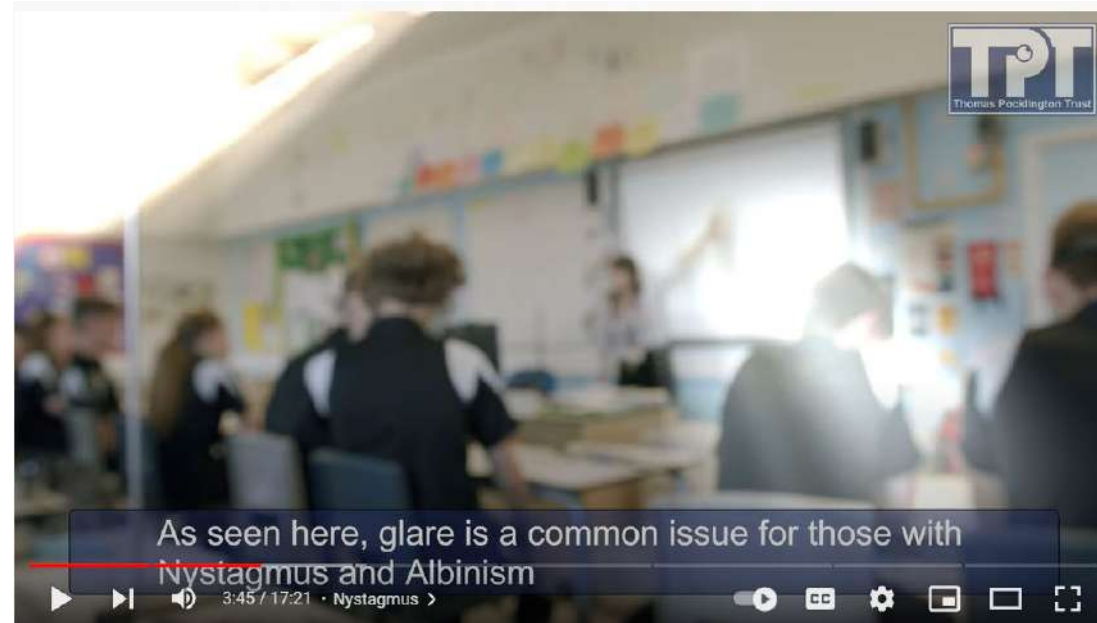
https://www.youtube.com/watch?v=Ey-UD5Vzu_Q



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What do we see 2?



Fluctuating vision, difficulty in changing focus, reduced distance vision and issues with glare are all captured in this TPT video simulation of nystagmus.

<https://www.youtube.com/watch?v=7BV0dxJ70>



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Nystagmus, by George, 11



- It means my eyes sometimes **move** without me wanting them to
- It means sometimes I find it **difficult** to see things
- It means I can only see about 3 metres **clearly**
- It **hurts** my eyes if I have to look at long distances

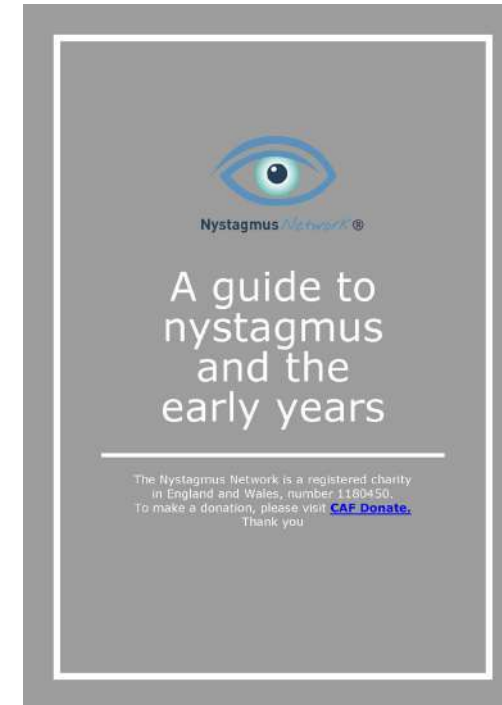


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Nystagmus affects everyone differently

- visual acuity
- depth perception
- facial recognition
- peripheral vision
- variability of vision
- general wellbeing
- mobility and gait



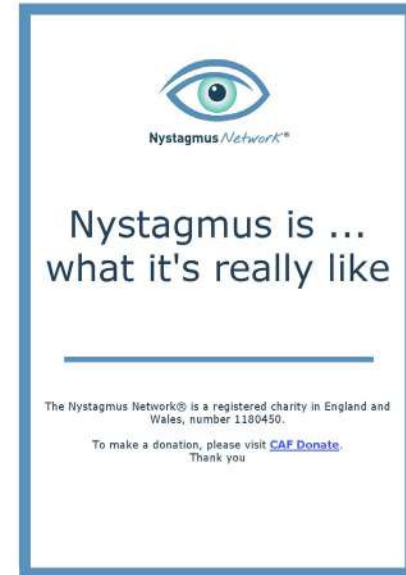


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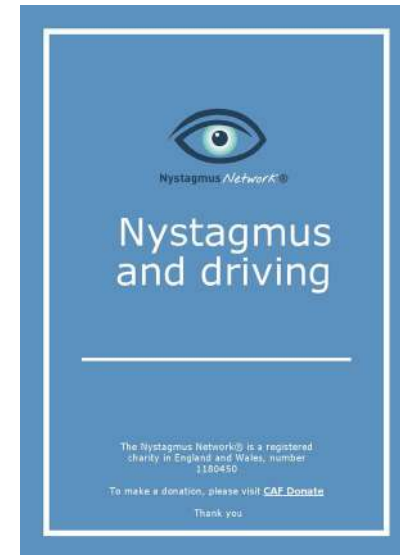
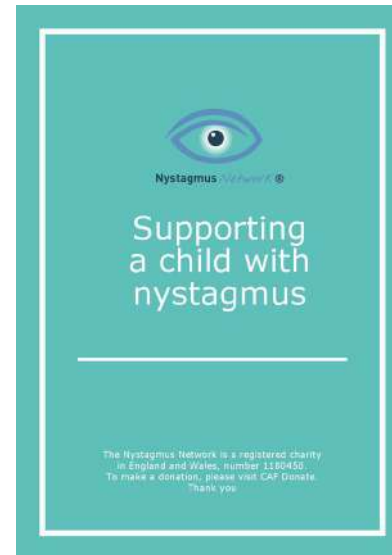
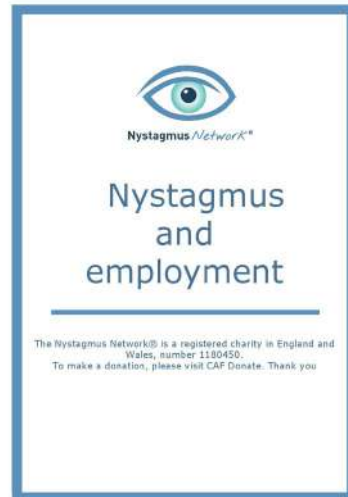
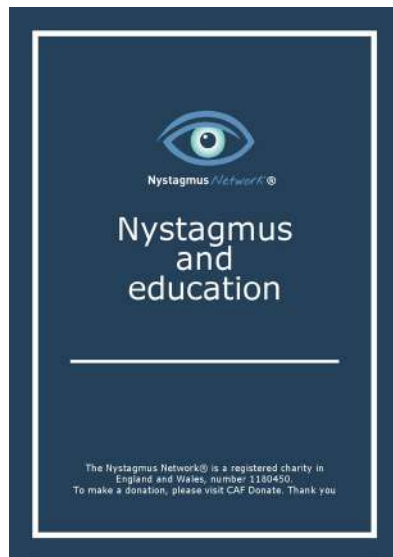
Social and emotional aspects of nystagmus

- eye contact, first impressions
- social cues and interactions
- recognising friends, joining in
- independence
- standing out from the crowd
- low self esteem
- isolation



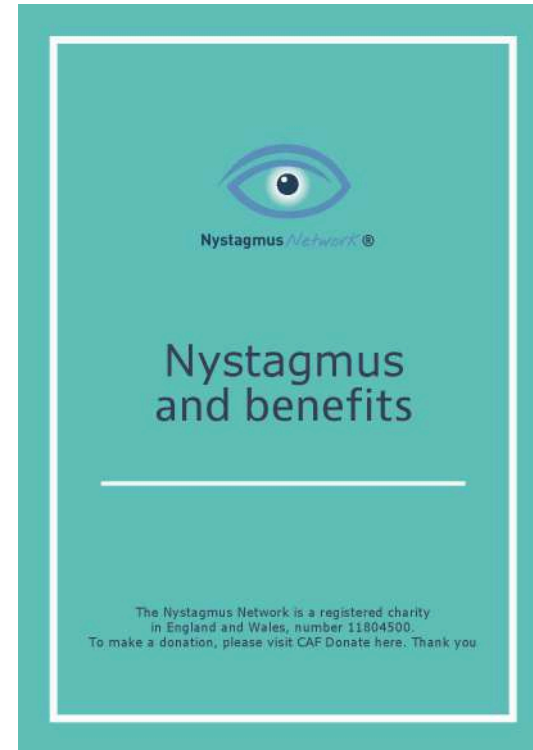
Support may be needed:

- around the home
- at school
- in the workplace
- out and about
- later in life



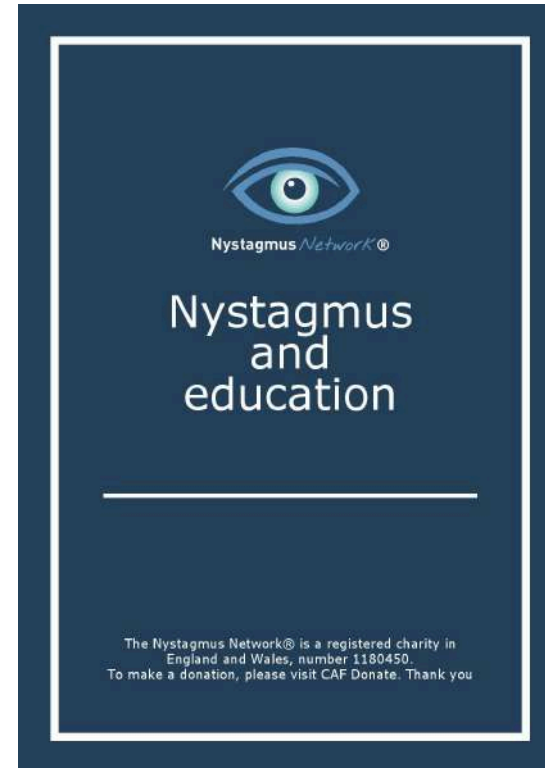
Benefits and nystagmus

- DLA
- means tested benefits
- non means tested benefits
- concessions

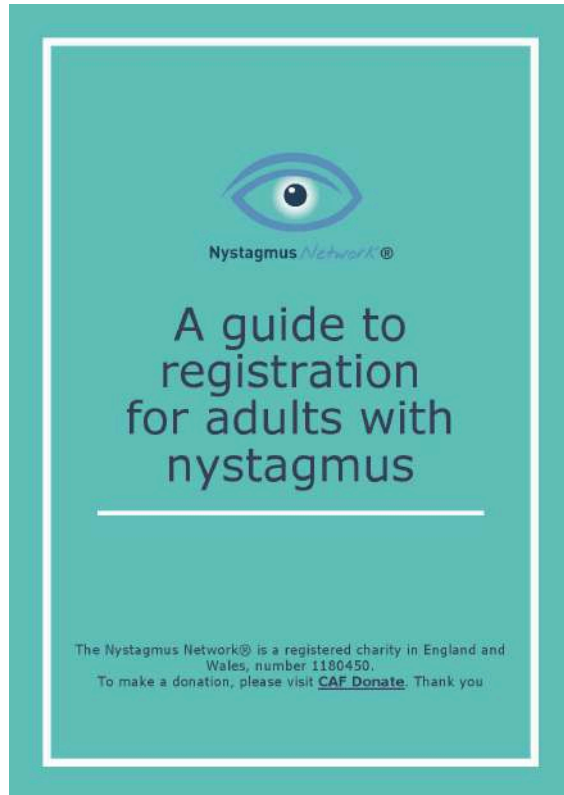


Education and nystagmus

- Nystagmus can affect the way a child accesses their learning
- The QTVI should make an assessment of needs
- A range of support and adaptations can be out in place



Registration



An Ophthalmologist can register a child as visually impaired because of the the impact of nystagmus on day-to-day life and ability to undertake everyday tasks

Registrations brings access to support, benefits and concessions



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Nystagmus **Network**
– we're here to support **adults**
with nystagmus, **parents** and
their **children**

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for information and support

call **01427 718093**



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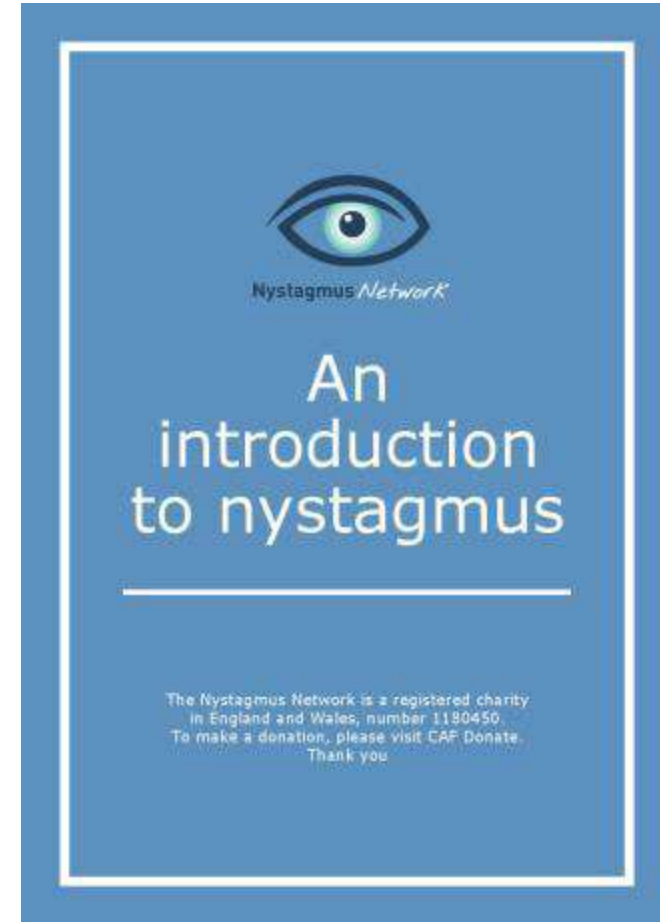


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Our **free** to
download
booklets
are available
from

www.nystagmusnetwork.org





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Find us on Facebook



Group by Nystagmus Network

Nystagmus Network parents' group

Private group · 2.1K members



Joined ▾



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Our online group for **parents**

Please contact us
if you'd like to join
our monthly
Zoom get togethers.





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Treatment options

Glasses can't stop the nystagmus eye movements, but they can make the vision the best it can be.

- **Optical** It's important that any other eye conditions (short sight, long sight, astigmatism) are corrected.
- **Surgical** Squint surgery or moving a marked null point.
- **Medical** In some cases, medication can be helpful, but this is usually only for young adults.

Find out more and watch a video on our website here:

<https://nystagmusnetwork.org/congenital-nystagmus/treatment/>



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