



Vertical supranuclear gaze palsy

Vertical supranuclear gaze palsy is difficulty with upward and downward eye movement

What may happen

At first, the person may have difficulty moving their eyes up and down voluntarily. Parents may notice this when their child walks up and down stairs, or, if they are watching TV while sitting on the floor, their child will tilt their head instead of moving their eyes. In the later stages of the disease, vision may be impaired as eye movement decreases. Although the person can still see, their vision will be limited to a small central spot, meaning that it will take time for the person to register what they are seeing.

What you can do

As it can be difficult to determine how a person's eyesight is affected, ensuring you are in their line of vision when addressing them can help. Children can be offered lots of visual stimulation through play, which can help to develop communication skills.

The safety of a person who is mobile should be considered when they are on stairs or approaching kerbs or any obstacles, to avoid falls wherever possible.





How we managed ... one family's story

J has major problems looking up and down without moving her head at the same time. She frequently trips up at kerbs or falls over toys that the children have left on the floor, as she does not see them. We did not realise at first that she was having problems coming down stairs safely, but we did notice that the backs of her shoes were wearing out very quickly and we realised she was sliding her feet against the riser to keep herself safe without looking down. It seems to have been her way of subconsciously compensating.

Who can help?

Adaptations around the home can be helpful in making life more manageable. An occupational therapist will be able to advise you on useful devices and aids.

This leaflet forms part of a resource pack published by the Niemann-Pick Disease Group (UK). It is intended to be read in conjunction with the other parts of the pack. If you do not have the other documents in the pack or you would like further information, please contact us at the email address below.

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