Epilepsy with eyelid myoclonia (EEM)

Epilepsy with eyelid myoclonia (EEM) is a rare epilepsy syndrome in children. Children with EEM are sensitive to bright lights, and have seizures that cause their eyelids to jerk repeatedly. EEM is usually something that you have for life. Visit: https://www.epilepsy.org.uk/info/syndromes

Other names for epilepsy with eyelid myoclonia (EEM)

- Jeavons syndrome
- Eyelid myoclonia with absences (EMA)
- Sunflower syndrome or EEM with prominent photic induction

Who gets EEM?

EEM most often starts in children aged between 6 and 8 years. But it can start any time between the ages of 2 and 14 years. It’s more common in girls than boys. It’s not linked to any other health problems or problems at birth.

Many children with EEM have a family history of epilepsy.

Symptoms

If your child has EEM, they may have multiple seizures every day. The seizures usually only last for 1 to 3 seconds. Children with EEM are photosensitive. This means that the seizures are triggered by flickering light. They can also come on when your child closes their eyes. Visit: https://www.epilepsy.org.uk/info/photosensitive-epilepsy

During a seizure, your child may have the following symptoms:

- Their eyelids may jerk rhythmically and repeatedly (eyelid myoclonia)
- Their eyeballs may roll upwards, so you can see the white part of their eyes
- Their head may jerk backwards

Some children may have absence seizures at the same time as eyelid myoclonia. This means they also lose some awareness and may not respond. Visit: https://www.epilepsy.org.uk/info/seizures/absence-seizures

Children with EEM may also get tonic-clonic seizures. A child having this type of seizure may fall unconscious and make jerking movements with their arms and legs. This type of seizure doesn’t happen often, and it’s usually over within 2 to 3 minutes. They’re more likely when your child is tired, or they’re exposed to bright lights. Visit: https://www.epilepsy.org.uk/info/seizures/tonic-clonic

Some children have a particular type of EEM, where they actively trigger seizures themselves. They do this by turning towards a light and waving their hand in front of their eyes, or using other methods to create a flickering effect. This used to be called Sunflower syndrome, but is now called EEM with prominent photic induction.

Diagnosis

Your child should see a specialist doctor called a paediatrician for an assessment. The paediatrician will examine your child and take a record of exactly what happens during their seizures. If you’re able to take a video recording of the seizures, this can sometimes be helpful. This may be difficult though, because the seizures only last a few seconds.
Your child’s doctor may suggest some tests to confirm a diagnosis. This may include an EEG (electroencephalogram) to look at electrical activity in the brain. This test can be particularly helpful if your child has a seizure while the EEG is being done. The EEG should show if your child has photosensitivity. Visit: https://www.epilepsy.org.uk/info/diagnosis/egg-electroencephalogram

Other tests, such as brain scans, aren’t usually needed to diagnose EEM. But your doctor may suggest them if they need to rule out other conditions or other epilepsy syndromes.

Treatment

Your child’s doctor may prescribe epilepsy medicines to help control your child’s seizures. These may include:

- Sodium valproate
- Lamotrigine
- Ethosuximide
- Levetiracetam

Visit: https://www.epilepsy.org.uk/info/treatment/anti-epileptic-drug-treatment

Epilepsy medicines can often help to stop tonic-clonic seizures. But the eyelid myoclonia symptoms can be more difficult to get under control with medicines.

Information about treatments for children can be found on the Medicines for Children website. Visit: http://www.medicinesforchildren.org.uk/

If your child has EEM with prominent photic induction, and is actively triggering seizures, their doctor may suggest ways to manage their behaviour. This can be difficult, particularly as many children also have learning disabilities.

Other things you can do to help include using:

- Wide-brimmed hats
- Wraparound sunglasses can help to reduce exposure to the light
- Glasses with special dark blue lenses (called Z1 lenses)

Outlook

EEM can be difficult to treat. And it’s usually something that you have for life. But as your child gets older, their seizures may become less frequent. Their sensitivity to light usually reduces too, but rarely goes away completely.

Children with EEM may sometimes have learning difficulties, although this isn’t always the case. It’s more likely in those children with prominent photic induction. With this form of EEM, around half of children have learning disabilities or problems with attention.

Your child’s doctor should be able to advise you on getting support in these areas if needed. We also have more information on how epilepsy can affect learning and behaviour. Visit: https://www.epilepsy.org.uk/living/education-and-epilepsy/learning-and-behaviour

Support

Contact
Charity for families with disabled children
Freephone helpline: 0808 808 3555
Email: helpline@contact.org.uk
About this information

This information is written by Epilepsy Action’s advice and information team, with guidance and input from people living with epilepsy, and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the information, please contact us at: epilepsy.org.uk/about/feedback

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Your support
We hope you have found this information helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this:

- Call the Epilepsy Action fundraising team on 0113 210 8851
- Donate online at: epilepsy.org.uk/about/feedback
- Send a cheque payable to Epilepsy Action to the address below

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/involved/join or call 0113 210 8800.

Epilepsy Action Helpline
Freephone 0808 800 5050 or email helpline@epilepsy.org.uk

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