



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Acute disseminated encephalomyelitis (ADEM)

What is acute disseminated encephalomyelitis (ADEM)?

ADEM is a rare inflammatory condition that affects the brain and spinal cord. It often follows on from a minor infection such as a cold, and is the result of the immune system becoming mis-programmed, and activating immune cells to attack the healthy myelin (a fatty protective coating) covering the nerves.

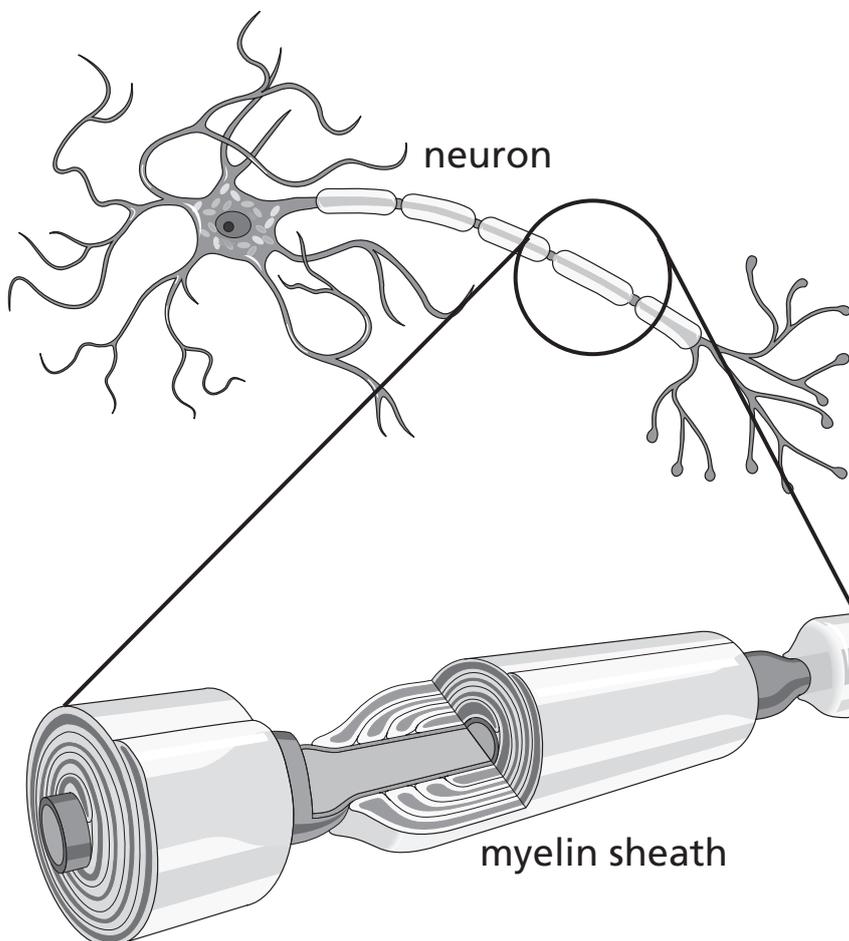
What are the symptoms and signs of ADEM?

ADEM usually comes on quite quickly over hours to days. Symptoms may include nausea and vomiting, headache, irritability and sleepiness, unsteadiness or inability to walk, problems with vision, weakness or tingling in certain areas of the body. In severe cases seizures can result. The symptoms depend on where in the brain or spinal cord the inflammation and swelling is occurring.

How is ADEM diagnosed?

ADEM can be difficult to diagnose and often needs specialist tests. It is also important for the doctors to consider other possible causes of inflammation and infection in a similar way. To exclude these conditions, bloods tests and a lumbar puncture may need to be carried out. A lumbar puncture involves taking a tiny amount of cerebrospinal fluid (the fluid which surrounds the brain and spine) from the bottom of your spine. This is to check for the presence of particular proteins that might indicate inflammation.

An MRI scan of the brain (and sometimes the spine) will be the most helpful in making the diagnosis of ADEM. An MRI scan uses a magnetic field to take pictures of the brain and spine. It will enable the doctor to see whether the myelin around the brain and spinal cord has been damaged. Sometimes a dye (contrast) will need to be given intravenously (into a vein using a needle) during the scan, to help see the areas involved more clearly. Treatment for other causes, such as brain infection (encephalitis), may be started before this is done.





How is ADEM treated?

Steroid treatment can help reduce some symptoms and may stop new symptoms from developing. Once the diagnosis is made, steroids are usually given into a vein once a day for the next three to five days. Most young people start to get better quickly, and make a full recovery. If though there is no sign of improvement within a few days, other treatments may need to be considered.

What is the prognosis of ADEM?

For most children, recovery begins within days and continues for up to one year. Some patients continue to have symptoms such as blurred vision, weakness or numbness.

Will my child get ADEM again?

ADEM usually only occurs once, sometimes twice. Multiple attacks are very rare so may require further tests and discussion to confirm the diagnosis.

Will my child go on to develop multiple sclerosis (MS)?

ADEM and MS are both conditions caused by the body's immune system becoming mis-programmed and attacking the myelin covering of the central nervous system. A small number of children with ADEM will go on and develop further attacks of demyelination and possibly MS. However, the typical features seen in ADEM of sleepiness, irritability and fever are uncommon in a first attack of MS. Your doctor will be able to discuss this further with you based on your child's specific symptoms and MRI findings. You may also be asked to help in research to enable us in time to answer these questions better.

What happens next?

Once the team looking after your child feels that the time is right, you will be discharged either to your local hospital or home. If there are no new concerns, your local paediatrician will continue to care for your child. If there are any new concerns, we will see you back in a clinic at GOSH.

We suggest any routine vaccination is delayed if possible for at least six months after the ADEM attack, but clearly this needs to be balanced against the risks of being unvaccinated.

Further information and support

There are several organisations in the UK offering support and advice about ADEM and life afterwards.

- The **MS Society** supports people affected by multiple sclerosis and other demyelinating disorders. Call their helpline on 0808 800 8000 or visit their website at www.mssociety.org.uk
- You can call the **Encephalitis Society** on 01653 699 599 or visit their website at www.encephalitis.info
- The **Transverse Myelitis Society** may also be able to help. Their helpline number is 020 8568 0350 and their website is at www.myelitis.org.uk
- The **British Trust for the Myelin Project** supports researchers and other people with an interest in demyelinating disorders. You can call them on 0161 292 3191 or visit their website at www.myelinproject.co.uk