



Multiple Sclerosis Society

March 2012

MS Essentials Factsheet

ADEM (Acute disseminated encephalomyelitis)

What is ADEM?

ADEM (acute disseminated encephalomyelitis) is a rare 'inflammatory demyelinating condition' of the brain and spinal cord. Inflammation damages the protective covering around the nerve fibres (the 'myelin'). It usually affects children, most commonly under the age of 10.¹

Like MS, ADEM is thought to be an autoimmune condition, in which the body's immune system mistakenly attacks its own brain tissue. As both the symptoms and the test results for ADEM can be similar to those of MS, it may be difficult for doctors to distinguish between the two. However, ADEM tends to only occur once, so if someone has a number of relapses over time this would usually suggest they have MS.²

What are the symptoms?

ADEM usually starts quite quickly, with symptoms such as headache, stiff neck, drowsiness or impaired awareness (termed 'encephalopathy'). In severe cases, the person may have seizures or go into a coma. In addition, they may also have neurological symptoms, which can be similar to MS – such as optic neuritis (inflammation of the optic nerve), problems with balance, or they may lose the ability to walk or stand, often with inflammation in the spinal cord. Other symptoms could include weakness, numbness or tingling in the arms or legs; bladder or bowel problems; or speech disturbance.

Symptoms of ADEM typically last a few days, and often resolve quickly with treatment. Less commonly, symptoms can last a few weeks to months.

How is it diagnosed?

ADEM would usually be diagnosed on the basis of the person's symptoms and the findings of an MRI scan. Doctors may also carry out a lumbar puncture, in which a small amount of spinal fluid is drawn from the base of the spine.

Since many people with ADEM have fever and other symptoms of infection, it's common for them to be treated with antibiotics and antiviral therapy until tests for infection come back negative.

How common is it?

Rare. It's not known how many cases of ADEM there are in a year. Not every hospital in the UK will see a case every year, although larger hospitals may see several. Studies in other countries have found that it affects fewer than four in every million children per year.^{3,4,5}

The number of adults diagnosed each year is not known, but it is much less common in adulthood.

What causes ADEM?

It's not clear exactly what causes ADEM. In some cases, symptoms come on following a viral infection or very rarely following vaccination. The infection itself doesn't cause the damage to nerve cells. Instead, it is most likely to be the body's own immune system overreacting to the infection which causes the damage.⁶

How is ADEM treated?

Treatment for ADEM is aimed at suppressing the inflammation in the brain. Most people will be treated with high doses of steroids. This would usually be a three to five-day course of methylprednisolone given by drip. If necessary, this would be followed by a 'tapering schedule' of oral steroids (meaning that the amount the person takes would be gradually reduced).

If steroids don't work, there are other treatments that can be tried, including plasma exchange or intravenous immunoglobulin therapy (a blood product given by drip). Physiotherapy and occupational therapy will help improve strength, balance and function.

How good is recovery?

More than 85 per cent of people with ADEM make a complete recovery – usually quickly, although it can sometimes take weeks, or even months.⁷

In cases where someone does not make a full recovery, their remaining symptoms are likely to be mild cognitive impairments or behavioural changes. If this happens, it's important that they get appropriate rehabilitation support. This could include psychologists, speech and language therapists and additionally, in the case of a child with ADEM, any extra support they need at school or college.

In a small number of cases, ADEM can be more severe – even fatal. One study comparing ADEM in children and adults found that adults tended to be more severely affected, with worse recovery rates.⁸

Will it come back?

In most cases, it won't. In about 80 per cent of cases, it is a single isolated incident.⁷

Very rarely, people can have more than one ADEM attack. Some people may have an initial attack that appears to be ADEM, but then experience further non-ADEM attacks, leading to a diagnosis of MS.⁹

References

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Useful sources of information

The Encephalitis Society

Information, advice and support. Includes factsheets on ADEM in adults and children.

www.encephalitis.info

The Transverse Myelitis Association

Information and online forums for people with the spectrum disorders of ADEM, neuromyelitis optica, optic neuritis and transverse myelitis.

www.myelitis.org/adem

Contact a family

Support for families with a disabled child.

www.cafamily.org.uk

Encephalitis Global

Sharing information and support between encephalitis survivors, caregivers and loved ones.

www.encephalitis.org

Encephalitis Cases

Stories from encephalitis survivors and caregivers.

www.1halloween.net/encephalitis/

Survivors Plus

For encephalitis survivors, caregivers, families and friends.

www.eglobal.ning.com

National Childhood Encephalitis Parents' Help Group

Talk about issues related to children who have survived encephalitis. This is a parents' email exchange network.
www.groups.yahoo.com/group/Nceph2Group

The UK & Ireland Childhood CNS Inflammatory

Demyelination Working Group
www.childdemyelination.org.uk

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MS Helpline

The MS Helpline offers confidential emotional support and information to anyone affected by MS, including family, friends, carers, newly diagnosed or those who have lived with the condition for many years. Calls can be made in over 150 different languages, via an interpreter. Call freephone 0808 800 8000 (weekdays 9am-9pm, except bank holidays) or email helpline@mssociety.org.uk

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