Acute Disseminated Encephalomyelitis (ADEM)

How common is it?

ADEM is more common in children than in adults, most commonly occurring in under ten-year-olds. About three per cent of all cases are reported in adults. ADEM can come on after viral infections like measles, and after vaccinations, like flu jabs. In the UK, regional centres for children and adolescents see several cases a year - but probably fewer than ten. This means ADEM will not be seen every year in every district hospital and many GPs will never have come across it.

What are the symptoms?

ADEM commonly begins with symptoms like fever, headache, stiff neck and vomiting. This can be followed by feeling dazed and confused, delirious and, occasionally, entering into coma. There may be loss of balance and an inability to walk or stand. Seizures can occur in the course of the illness in up to one third of children, but the seizures are not usually difficult to control. In some people, these symptoms can last a few weeks to a month. For others, symptoms can come and go more quickly - over a few days.
**What are the causes?**

ADEM has been reported as a rare complication of childhood illnesses, including chickenpox, mumps, or measles. Vaccination for these helps to reduce the risks. Chickenpox and non-specific respiratory infections are now the most common causes of ADEM, but such cases are also extremely rare. Damage to nerve cells is caused not by a viral infection, but most likely by an autoimmune reaction, in which the body’s immune system attacks its own brain tissue.

**How is it diagnosed?**

Early symptoms of ADEM are similar to an acute relapse in MS and it can be difficult to determine the difference, especially in the early stages. The only sure way to distinguish between MS and ADEM is the presence of relapses over time, which can indicate MS.³

While tests are being done, people are likely to be hospitalised and given antibiotics and antiviral treatment through a drip. This precaution is taken because the symptoms may mimic those of meningitis or viral encephalitis. Encephalitis is inflammation (swelling) of the brain tissue. It is caused either by infection, usually viral, or by an autoimmune disease. This is when your immune system tries to fight off an infection but by mistake, attacks parts of your body at the same time. Tests could include blood tests and possibly a lumbar puncture (where a small amount of spinal fluid is taken from the base of spine).

MRI scans of the brain and spinal cord are often a very reliable way to show up ADEM or MS.⁴

**How is it treated?**

High doses of steroids can often be very successful.⁵ Most often a three-day course of an intravenous steroid called methyl prednisolone is given. Steroids can also be given orally for a few weeks, with a tailing off schedule.
How good is recovery?

Most ADEM cases just happen once and have a favourable outcome. However, a few cases are severe or even fatal. Up to 75 per cent of cases have a complete recovery, but it can take weeks, or even months. Reports suggest that in children who do not make a full recovery, their areas for support are likely to be in the field of learning to a mild degree. In children and in adults, some degree of physical disability may remain depending on any nerve damage from the onset of the condition.

The team involved in rehabilitation is likely to be made up of physical therapists, speech and language therapists, psychologists and the teaching service depending on the individual's particular needs. Adults may also require some vocational rehabilitation to help them back to work.

Will it come back?

Most of these episodes are isolated and do not recur. However sometimes there is a recurrence, which can present differently, or with a different set of neurological symptoms from the first episode. In some recurring cases, especially where it doesn't look exactly like ADEM, those affected have been shown to be at some greater risk of developing MS in later life.

References


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**Useful sources of information**

**The Encephalitis Society**
Information, advice and support.
www.encephalitis.info

**Encephalitis Ireland**
Irish Encephalitis Survivors Welcome Support Group and Website
www.encephalitisireland.ie

**Encephalitis Global**
Sharing information and support between encephalitis survivors, caregivers and loved ones.
www.encephalitisglobal.com

**Stories and support on the net about Encephalitis**
Encephalitis survivors and caregivers post stories to this web site.
www.1halloween.net/encephalitis

**Survivors Plus**
Encephalitis survivors and caregivers, families and friends.
www.eglobal.ning.com

**The Transverse Myelitis Association**
www.myelitis.org/adem
Advocates for children, adolescents, and adults with the spectrum disorders of acute disseminated encephalomyelitis, neuromyelitis optica, optic neuritis and transverse myelitis.
N-C.E.P.H.- National Childhood Encephalitis Parent's Help Group
Talk about issues related to children who have survived encephalitis. This is a parent's email exchange network.
www.groups.yahoo.com/group/Nceph2Group

Contact a family
Talk to other families in the same position for advice and support.
www.cafamily.org.uk

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