

A School Guide for Students with ADEM

What is ADEM? (Acute disseminated encephalomyelitis)

ADEM is an intense attack of inflammation in the brain, spinal cord and occasionally the optic nerve. This causes damage to the myelin—the protective covering around the nerve fibers in the central nervous system. The attack lasts several weeks to months. ADEM is sometimes mistaken for a severe first attack of multiple sclerosis (MS), since some of the symptoms of the two disorders are similar. ADEM usually consists of a single attack, while MS features many attacks over the course of time. It is important to differentiate between ADEM and MS because long term care differs significantly. Children are more likely than adults to have ADEM.

How can ADEM affect school performance?

The symptoms of ADEM appear rapidly, beginning with the following:

- Fever
- Fatigue
- Headache
- Nausea and vomiting
- Excessive irritability
- Confusion
- Seizures (in more severe cases)
- Coma (in more severe cases)

Symptoms that relate to the nervous system could include:

- Visual disturbances (if optic nerve is affected)
- Weakness in single or multiple limbs
- Difficulty coordinating muscle movements
- Difficulty walking
- Incontinence of bladder or bowels

How can schools assist students with ADEM?

Academic:

- Start academic interventions right away under Section 504 or IDEA for Other Health Impairment
- Assess for PT/OT and assistive technology needs, as soon as possible
- May need visual assessment if vision is disturbed
- Have reading assignments on tape or enlarge written material if eyes are affected
- May need assistive devices such as wheel chair or walker for a period of time
- Set up homebound services if student will be out four or more consecutive weeks

- Give tests orally and no grades for handwriting, if hands are affected
- Use of laptop or computer for homework, essays, quizzes and notes so hands are not fatigued
- Provide hard copy of notes prior to class, or record class lecture
- Provide detailed schedule of assignments or an organizer
- Avoid work overload on homework and/or class work
- Place core classes early in the day to avoid fatigue

Social/Emotional:

- Conduct a staff in-service for any staff involved with the student
- Provide counseling to address any emotional or social stress
- Select a support person to address any concerns the student may have
- Communicate frequently among student, parents, school nurse, and medical team

Physical:

- Include rest period in student's schedule due to fatigue
- Consider having a set of text books at home and one in each classroom
- Utilize an elevator pass and not the stairs, if legs are affected
- Schedule major tests and projects on separate dates to avoid fatigue
- Provide breaks for student during standardized testing to avoid fatigue
- Involve student in school activities, but with possible limitations (i.e. some sports, low stadium seating, etc.)
- Provide extra travel time between classes
- Provide preferential seating
- Provide a permanent nurse pass and bathroom pass
- Keep a change of clothes at school if bowels or bladder are affected
- Avoid fatigue, stress, extreme temperatures, and exposure to illness
- May need adaptive P.E.

Resources:

www.nationalmssociety.org

www.ninds.nih.gov/acute_encephalomyelitis.htm

www.ucsfbenioffchildrens.org/conditions/acute_disseminated_encephalomyelitis/