

Back-to-School Kit

Acute Disseminated Encephalomyelitis (ADEM)

Below is a brief summary of the disorder affecting your student. While the presentation of symptoms may vary, this overview provides general information on the onset and impacts of the disorder. We hope this information is helpful and assists you in supporting your student as they navigate the education system while also managing their condition.

What is acute disseminated encephalomyelitis, and who gets it?

Acute disseminated encephalomyelitis, or ADEM, is a rare inflammatory disorder in which the body's immune system mistakenly attacks the brain and spinal cord. ADEM is more common in children and adolescents than it is in adults, but is still incredibly rare.

What are the initial symptoms of ADEM, and what are the chronic symptoms those with the disorder often manage long-term?

For most rare neuroimmune disorders like ADEM, there is an initial onset where the body attacks itself. The aftereffects of attacks can lead to life-altering long-term symptoms that the person with the condition will need to manage. If the condition is monophasic, which means it only results in one attack at the onset, the child will only need to manage the symptoms from the damage of that single attack. If the condition is recurrent, the child will have continual attacks unless an effective treatment option is found. ADEM is most often monophasic but can be recurrent.

The initial presentation of this rare neuroimmune disorder tends to include fever, headache, and vomiting. Encephalopathy (abnormal functioning of the brain) is a characteristic feature of ADEM and usually develops rapidly. This attack often results in chronic symptoms such as an altered level of consciousness (sleepiness or even coma), cognitive dysfunction (difficulty with attention, memory, problem-solving, etc), behavioral changes, and seizures. Other common aftereffects of ADEM include decreased voluntary movement, muscle weakness, decreased coordination, and abnormalities in eye and face movement. Inflammation can occur in the brain, optic nerves, and/or spinal cord. The optic nerve connects the back of your eye to your brain and sends signals that allow you to see. The spinal cord sends messages from the brain to the rest of the body that allow you to move and feel. Thus, a child or adult with ADEM can also have symptoms such as impaired vision and eye pain, and/or motor and sensory abnormalities.

What are common accommodations students with ADEM might need to access education?

The accommodations necessary for children with ADEM can vary depending on the severity of its impact on the child, but the following are accommodations more frequently requested by those with ADEM:

- Longer exam periods (cognitive dysfunction may slow function)
- Ability to sit and rest when needed (there may be some mobility issues present)
- Different ways of receiving material (may need visual, audible, or tactile information)
- Preferential seating (may need the ability to sit close to the teacher to keep focus)
- Schedule adjustments (may need leniency on when assignments are due)

What does short-term treatment look like for those with ADEM?

The first-line acute (short-term) treatment for ADEM is high-dose intravenous corticosteroids for three to five days. Intravenous immunoglobulin (IVIG), an intravenous infusion of antibodies taken from thousands of healthy people, may also be used. These extra antibodies overwhelm the immune system and prevent it from attacking healthy proteins. Plasma Exchange (PLEX) can be considered in very aggressive forms of ADEM or if there is limited response to corticosteroids and/or IVIG. PLEX is a process



that involves the removal and return of some of a person's blood to remove harmful substances such as those contributing to ADEM.

What does the long-term management of ADEM look like?

Recovery from an episode of ADEM typically occurs over 4 to 6 weeks, with the majority of children making a significant recovery. However, some may experience residual symptoms such as weakness, sensory difficulties, bowel/bladder dysfunction, headaches, and issues with attention, short-term memory, and decision-making. Most children with ADEM have a monophasic course, experiencing only one episode, but up to 36% may relapse. After the acute phase, rehabilitation is incredibly important for regaining strength and function. Collaboration with occupational and physical therapists can prevent complications like skin problems and stiffness due to immobility.

For long-term management, it's important to address chronic health problems and equipment needs. Supporting the student's return to school and community reintegration is essential. This may include:

- Adjusting classroom activities to accommodate physical and cognitive challenges.
- Providing additional time for assignments and tests.
- Ensuring access to necessary medical equipment.
- Implementing strategies for improving attention and memory in the classroom.

Children with ADEM may experience depression or anxiety, requiring careful monitoring and support. As a teacher, being aware of these potential challenges and fostering a supportive environment can make a big difference. Encourage open communication with the child and their family to better understand and address their needs. Family education is another important element when managing the challenges of returning to daily life. Providing resources and support to families helps them cope with the physical and emotional impacts of ADEM. By understanding the long-term management of ADEM, you can play an important role in supporting your student's recovery and reintegration, helping them thrive academically and socially despite the challenges they may face.

Is ADEM genetic or contagious?

Currently, there is no specific gene associated with ADEM. However, ADEM is likely triggered by something in the environment (infection or vaccine) in people who have certain genetic makeups that make them more likely to have inflammation. This does not mean that ADEM itself is at all contagious—the ADEM genes are likely already present in the body and are triggered, not transmitted.

How can children cope with an ADEM diagnosis?

Adapting to a "new normal" is difficult, and every person with ADEM copes differently. Some have found it easier to cope after learning more about ADEM from their doctors and getting a better understanding of how ADEM will affect their lives. However, some parents may choose not to keep their child informed on some of the difficult aspects of having the condition due to the age of the child. We recommend speaking with the parents of the child to determine how much the child knows about their own condition.

Learn More

SRNA
wearesrna.org

Back-to-School Kit
Teacher's Guide
srna.ngo/bts-tg

More information on ADEM
srna.ngo/adem

