

The International OMS Study Group

Dear Parents and Teachers of OMS/DES Children,

We would like to share this document with you to help you develop a better understanding of OMS/DES and how it impacts a child's life, particularly in the educational environment. We would appreciate your feedback on this document to let us know if this information is helpful and if there may be any additional information that will help you to support these unique children at school.

Please provide your feedback to Kitty Petty, at Catherine.Petty@childrens.harvard.edu .

We are grateful to the Dancing Eye Syndrome Support Trust and OMSLife Foundation for the opportunity to provide you with this material.

Best Regards,

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Steering Committee

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Family Education Guide

A School Guide for Supporting Children and Teenagers Diagnosed with Opsoclonus Myoclonus Ataxia Syndrome (also known as Dancing Eye Syndrome)

What is Opsoclonus Myoclonus Ataxia Syndrome (OMS)?

Opsoclonus-myoclonus-ataxia syndrome (OMS), also referred to as “Dancing Eyes Syndrome” (DES) is a rare autoimmune disease that affects the brain. Autoimmune diseases cause the body’s immune system to react against itself and attack its own healthy tissue. In OMS/DES, the immune system reacts against certain components of the brain. The main target of the attack is believed to be the cerebellum. This attack is what causes the symptoms of OMS/DES. **Initially these symptoms can be severe**, and include spontaneous, abnormal, chaotic eye movements (opsoclonus), spontaneous random limb jerking (myoclonus), and incoordination (ataxia). **Even if these physical symptoms resolve**, up to 70% of patients may experience residual cognitive and behavioral symptoms, including speech and language problems and aggression. Other residual symptoms may include reading difficulties, dysregulation and anxiety.

OMS/DES Demographics

- **Pediatric OMS/DES onset** (the age at which symptoms appear) occurs in most patients before 3 years of age.
- **The average age of onset** in pediatric OMS/DES is approximately 18 months.
- **OMS/DES is frequently associated with neuroblastoma**, a type of cancer that appears most often in infants and small children.
- Some children have a single (or monophasic) course of the disease, **but most children experience one or more relapses**. Other children have what is called a relapsing-remitting course, which means that the symptoms come and go over extended time.

OMS/DES Symptoms

- Each student with OMS/DES is unique. However, **students with OMS/DES may experience physical, cognitive and emotional symptoms**. These symptoms can be mild or severe, depending upon the severity of the disease. Further, they may fluctuate in severity over time, with variations in the underlying condition.

Physical Symptoms

- **Opsoclonus** – Rapid, involuntary eye movements. This symptom is most often seen in the acute stage of the disease, however reappearance may signal relapse.
- **Myoclonus** – Involuntary muscle movements. These involuntary movements may appear in the child’s limbs, shoulders, or torso.
- **Ataxia** – Unsteadiness. Children experiencing ataxia may have difficulty standing up, walking, running, and maintaining balance.
- **Tremulousness** (tremor)
- **Dizziness**
- **Difficulties with behavior and mood**, including episodes of rage.

- **Sleep disorder** – Students may appear to be fatigued, due to loss of sleep or interrupted sleep patterns.

Cognitive Symptoms

Children with OMS/DES are highly vulnerable to cognitive impairment and learning difficulties. These cognitive symptoms are similar to symptoms seen in other conditions involving injury to the cerebellum, and may occur even if the child has no apparent or detectable physical symptoms of OMS/DES. Students with OMS/DES should be individually evaluated to determine their individual learning strengths and weaknesses. Once these are identified, individualized teaching strategies may be implemented to provide students with OMS/DES with appropriate academic support. Some of the more common learning difficulties students with OMS/DES may encounter include the following:

➤ **Verbal learning and memory:**

The student may have difficulty recalling or retrieving information that was previously learned. This may become more apparent as the curriculum becomes more challenging, particularly in math and other core subjects. These students may benefit from frequent repetition of information and being given directions in both visual and verbal formats.

➤ **Processing speed:**

The student may take longer than peers to process information. This may be evident when the student is required to copy or scan visual information, take notes, copy information from the board, complete worksheets, or “think fast”, especially on new or unfamiliar tasks. These students may benefit from extra time to complete assignments and tests, reducing the number of items the student must complete, and recording teacher lessons.

➤ **Executive functioning (cognitive flexibility):**

The student may have difficulty shifting their attention between tasks or activities quickly, following multi-step directions, or prioritizing assignments. These students may benefit from breaking down tasks into smaller units and the use of flow diagrams or mind maps, along with verbal cues, written checklists, and graphic organizers.

➤ **Attention span:**

The amount or “chunk” of information a student is able to attend to or process at one time may be more limited than other students. They may also be easily distracted, and may “tune out” from what is going on in the classroom. These students may benefit from reduced distractions in their work area, dividing their work into smaller sections, asking them to orally summarize information that has been presented, and the use of verbal and nonverbal cueing to maintain attention.

➤ **Visual Perception and Spatial Awareness:**

A hindered ability to make sense of information taken in through the eyes (coordinating movement with what is seen, as in copying, writing, or catching a ball). These students may benefit from having extra time to process visual information,

visual prompts such as green/red dots for starting and finishing, adapted worksheets, and focusing on short sessions of concentrated effort.

➤ **Reading:**

Reading difficulties may include one, some, or all of these difficulties: rhyming, hearing individual sounds, struggling to sound out most words, reading quickly (fluency), understanding what is read (reading comprehension), following directions, re-telling a story avoidance of reading aloud. Early intervention is helpful. Research based reading programs (Orton Gillingham, Wilson, Lindamood Bell, Project Read) are effective to help remediate a child's reading deficits.

➤ **Receptive Language (e.g. listening comprehension) and Expressive Language (e.g. communication, speaking):**

A language disorder is an impairment in the ability to understand (receptive) or use words (expressive) in context, both verbally and nonverbally. Some characteristics include improper use of words and their meaning, inability to express ideas, inappropriate grammatical patterns, reduced vocabulary, and inability to follow directions and/or follow a presentation of new concepts. Students with OMS/DES may benefit from having information clarified, repeated or broken down into smaller segments, extra time to express themselves, and visual or auditory prompts.

➤ **Intellectual Disability**

➤ **Autism Spectrum Disorder (ASD) or autistic traits (features of autism but not meeting the diagnosis of ASD)**

In General...

Students encountering some or all of these learning difficulties can be successful at school. However, because each child is unique, **there is not one teaching program that applies to all students with OMS/DES**; instead, classroom instruction should be adapted for each child's individual needs, which, along with environmental modifications, will provide such students with greater opportunities for success.

Emotional Symptoms

Some OMS/DES patients experience intermittent or sustained periods of rage. Others may be dysregulated, have obsessive-compulsive symptoms, or experience anxiety. These symptoms may interfere with the student's ability to access the curriculum at school and with their social interactions at school and ability to make friends. Students experiencing these social and emotional symptoms may benefit from an array of school and home-based behavioral interventions and therapies, and/or medication. It may be helpful for an occupational therapist (OT) with sensory integration training evaluate the student to determine if OT can help to reduce sensory symptoms (sensitivity to noise, harsh light, odors, and touch, including sensitivity to clothing). A Functional Behavioral Assessment (FBA) can also be requested if a child is finding it difficult to maintain appropriate behaviors

at school. The FBA can be completed by a school behavioral therapist (often the school psychologist) or through an outside agency. A behavioral plan is developed to help a child receive positive reinforcements/incentives to help them improve behavior at school.

Relapses

Some children with OMS/DES may experience one or more relapses. Relapses can be unpredictable and very concerning. Some or all of the physical symptoms of the illness may reappear, including changes in behavior. Relapse may follow the onset of common childhood illnesses, such as the flu. Because of this, teaching and health personnel at the child's school should be familiarized with OMS/DES and its symptoms, so that they may alert parents/guardians to illnesses emerging at the school and respond accordingly.

OMS/DES medications

Children with OMS/DES are typically treated at onset of the illness and during relapse with daily steroids, and in many cases with infusions that take place at the hospital or an infusion center. Occasionally, these medications may cause flu-like illness, such as fatigue and/or vomiting. Sometimes they can alter the child's behavior and appetite.

School Absences & Support

Children experiencing acute onset of illness or relapse may have unpredictable school attendance. They may also need to miss school from time to time in order to attend medical visits or receive treatment.

Evaluation and Academic Support

Very young children with OMS/DES should be evaluated for early intervention services (children from birth to 3) as soon as possible. These services may include occupational therapy (to support fine motor skills); physical therapy (to support gross motor skills), speech and language therapy (to support speech and receptive and expressive language skills), and/or cognitive support to help with a child's overall learning.

School-aged students with OMS/DES should be evaluated by the school district or privately as early as possible (starting at age 3 years of age) **for a learning disability or cognitive delays and supported with an education plan that addresses their individual needs.** In the United States, this may be under a 504 Plan (starting at 5 yrs. of age) or Individualized Education Plan (IEP), as needed. In the United Kingdom, this may be through SEN (Special Education Needs) support or under an EHC Plan (Education Healthcare Plan). The Parents/Guardians of students with OMS/DES in countries other than the USA or UK should consult with their school districts to develop education plans that will address and meet the individual needs of these students.

For further information, this website offers useful information about the provision of special education and related services in European countries: <https://www.european-agency.org/>

Additional Resources:

United States:

<http://www.ldonline.org>

<http://idea.ed.gov>

<http://omslifefoundation.org>

United Kingdom:

<https://www.gov.uk/government/publications/send-guide-for-parents-and-carers>

<http://www.specialneedsuk.org>

<http://www.ehcplan.co.uk>

<https://www.european-agency.org>

<http://dancingeyes.org.uk>

<http://omslifefoundation.org>