

How to Help Support Your Child with OMS

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OMS Patients

- Patients with OMS often have behavior, attention, reading difficulties, anxiety as well as other difficulties.
- Sometimes a school denies an IEP/504 Plan or provides minimal support due to their lack of understanding of OMS.

An OMS information sheet is available through omslifefoundation.org

New Patient

- We recently saw a 20-month-old, newly diagnosed boy with OMS.
 - A neuroblastoma was found and he was about to have surgery. His parents and extended family were concerned.
 - This child began to have emotional outbursts - a common problem with OMS patients.
- We met with his parents and offered some suggestions:
 - As children with OMS often have sensory issues, we suggested that his parents try to keep the environment as calm as possible.
 - His parents mentioned that many family members and friends were visiting them and it was noisy, loud, and their son's schedule was off.

OMS Patients

- Suggest that they try to keep his schedule as normal as possible to provide predictability.
- Use soft voices and provide quiet activities to keep him interested.
- Understand that he is scared so continue to reassure him.
- Use sensory techniques to provide nonverbal calming activities.
- Regain confidence in their ability to understand and help their young son.
- His parents looked at each other and said, “This is what we were beginning to realize.” Parent’s instincts can be very strong.

Behaviors

- Many children with OMS exhibit behavior problems.
- Parents become frustrated and uncertain about what to do.
- Their child becomes frustrated, which exacerbates their behavior.
- Their teachers become frustrated, which exacerbates their behaviors even more.

Behavior Journey of an 8-Year-Old Girl

A Real-life Example

Behavior Journey of an 8-Year-Old Girl

- Mary was diagnosed with OMS when she was four.
- She had severe behavioral dysregulation until she began treatment.
- Day care and preschool went well with structured and supportive teachers.
- Her mother was also good about handling her behavior problems.
- Kindergarten went well and she made a lot of academic gains.

Behavior Journey of an 8-Year-Old Girl, cont.

- 1st grade – She started well, but then Mary began to get into trouble. Her teacher did not realize that she was on an IEP.
 - Once her teacher recognized this, Mary’s behaviors began to improve.
- Despite support, Mary’s teacher noted that she remained dysregulated and had emotional outbursts.
 - She noted that Mary did better with positive reinforcement versus scolding.
- April: Behaviors were worsening. She had no friends.
- June: Mary’s parents were so discouraged with their daughter’s performance at school, they hired an advocate.

Behavior Journey of an 8-Year-Old Girl, cont.

- September: Mary had a good start to her 2nd grade year, but by October her behaviors warranted a Functional Behavioral Assessment (FBA).
 - A BCBA wrote up a behavioral plan.
 - The focus was on Mary's negative behaviors.

Please note: A behavior plan should always focus on what a child should do versus what a child is doing wrong. “Negative attention getting” (what a child does when this is the only attention they are receiving) requires adults to tell a child what they should be doing, not what they are doing wrong. And, they should be given **lots of praise** when they are doing something well!!!!

- Behaviors continued to worsen. Mary was discouraged and angry.

Success of an 8-Year-Old Girl

- 3rd grade: Mary began to attend a charter/magnet school. Her teachers were positive and supportive.
- She has had no serious behavior problem for a year at school.
- She needs reminders of expectations of her behavior on occasion.
- She has made several friends.

The Power of Positive Reinforcement!

Book List for Parents of Children with Behavior Problems

- *Your Defiant Child; 8 Steps to Better Behavior* by Russell Barkley
- *The Challenging Child; Understanding, Raising, and Enjoying the Five Difficult Types of Children* by Stanley Greenspan
- *The Explosive Child; A new approach for understanding and parenting easily frustrated, chronically inflexible children* by Ross Greene
- *The Misunderstood Child; Understanding and coping with your child's learning disabilities* by Larry Silver
- *123 Magic. Effective discipline for children 2-12 (Video)* by Thomas Phelan

Reading Challenges

An Overview and Real-life Example

Reading Delays

- Many children with OMS struggle to learn to read.
- It's important to share this information with preschool and Kindergarten teachers.
- If your child continues to struggle with letter identification and phonics (the sounding out of letters), additional school support should be provided.
- If reading is a concern during the first grade, research-based reading supports should be provided.

Reading Support

- Research-based reading programs include:
 - Orton Gillingham
 - Wilson Reading
 - Lindamood Bell: Seeing Stars
 - Project Read
 - Foundations

Reading Support, cont.

- A child with OMS was struggling to learn to read. Suggested that they use a research-based reading program, but the school chose to use their reading program.
- Consequently, when he received a private neuropsychological evaluation in the fourth grade, he was reading at a late first to early second grade level.
- The school district is now providing him with Orton Gillingham and his reading is improving, but the child's self-esteem is low and he doesn't like school.

Reading - 4th Grader

- A 4th grade boy was diagnosed with OMS when he was young. He has chronic relapses.
- He has speech and language problems along with fine motor delays.
- Reading is a struggle for him.
- The school provided him with a lot of services: reading support, speech and language therapy as well as OT.
- Recent neuropsychological testing revealed that his single word reading is at grade level, but his decoding skills are in the low average range. His reading comprehension and rate were at grade level.

Reading – A 4th Grader, cont.

- He loves school.
- He participates in an inclusion class.
- He has friends.
- He remains on an IEP and receives 2.5 hours a week of support for each subject: writing, reading, mathematics.
- During the summer he receives academic tutoring.

Reading Goal on His IEP

- Here is an example of a good reading goal:
 - Sam will improve overall reading skills as measured by successful progress on 2/3 short term comprehension objectives:
 - Given text at his instructional level, Sam will answer inferential questions pertaining to character motivation, changes, feelings on 8 out of 10 trials.
 - Given text at his instructional level, Sam will answer inferential questions pertaining to overarching theme (fiction) or main idea (non-fiction) on 8 out of 10 trials.
 - Given text at his instructional level, Sam will use expected breath support, intonation, inflection, and rate as measured by a score of 2 or higher on 8 out of 10 trials.

Key: Set clear objectives with measurable goals

Suggestions of How to Help

- Monitor Reading Level: Ask for a grade level reading report every three months to help make sure that your child is making effective progress. This can be added to an IEP.
- Reject all or parts of a child's IEP to ensure they are receiving the best services.
- USA Today is written at a fourth to fifth grade level. Their articles are short and highly interesting. Use this to determine reading level as well as your child's reading level.
- Of note: One only needs a fourth to fifth grade reading level to be able to be independent in life.

Reading Supports

➤ Web sites:

- ldonline.org : The best learning disability website in the world.
 - Excellent articles and suggestions provided from the top LD teachers and professionals
 - Offers free weekly news letter
- learningalley.org: provider of electronic books read by a person
 - Excellent for literature
 - Provides free webinars on how to help struggling readers

➤ VoiceDream: \$10 app for text to speech with excellent voice quality

➤ Speech to text: Use the “memo” icon on an iPhone or an Android

Thank you

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