

Understanding the energy/sensory connection: mitochondrial disease

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One thousand to four thousand children are born every year with some form of mitochondrial disease in the United States, and approximately another 4,000 children will develop some strain of the disease by age 10.

These children are attending our schools and are increasingly receiving occupational therapy services within the school and clinic settings. It is important to know about this condition so that we can not only treat the child, but educate the teachers and parents as well.

What is mitochondrial disease? A very simplified explanation is that the power source in the cells is impaired causing failure of the body to transform sugars into cellular energy. Every muscle is filled with mitochondria; combining sugars or fats with oxygen to produce water and ATP (adenosine triphosphate (ATP), the essential energy molecule of all animals; including us!.)

When this does not occur properly, many other systems are negatively impacted.

Depending on which cells of the body are affected, symptoms may include:

- * Poor growth
- * Loss of muscle coordination, muscle weakness
- * Visual and/or hearing problems
- * Developmental delays, learning disabilities
- * Mental retardation
- * Heart, liver or kidney disease
- * Gastrointestinal disorders, severe constipation
- * Respiratory disorders
- * Diabetes
- * Increased risk of infection
- * Neurological problems, seizures
- * Thyroid dysfunction
- * Dementia (mental disorder characterized by confusion, disorientation and memory loss)

These children often seem to work in “spurts” and then “peter-out”, becoming lethargic and

finding it difficult to concentrate. It is essential to understand that these periods of fatigue are not due to the child “zoning out”, but rather total exhaustion from deep within the cellular level of their existence.

These conditions can directly impact the sensory systems ability to accurately interpret various sensory experiences. This may cause behavioral issues in the form of over or under reacting to situations; not being able to quickly respond during a school fire drill, follow a direction during physical education class, forgetting something that was just explained. All of these issues can complicate and impede both academic learning and emotional growth.

As occupational therapists, we are constantly addressing the strength and endurance. Interfacing these abilities with sensory processing for effective treatment interventions. Moreover, applying the concepts we can learn from these children to others that we treat can enhance our quality of care as well as our long-term outcomes.

Fatigue can cause anyone to become less precise in his or her general functional abilities. This is even truer for the child with mitochondrial disease. When the mitochondria (the power supplier) is not working properly, the body cannot function as it should.

- the brain does not process information correctly
- muscles start to twitch and may become spastic and/or weak
- heart rate can become erratic
- vision may become impaired
- sensory processing can become skewed

It is because of some or all of the above that these children are often referred to occupational therapy.

An effective treatment plan should teach:

- Energy conservation
- Body positioning and postural control
- Stress management and relaxation techniques
- Fine motor training is essential, often these children have difficulty holding a pencil and cannot keep up with their peers even at the preschool level
- Visual perceptual training
- Stimulate sensory processing and sensory interpretation
- Task organization, inclusive of, but not limited to time on/off task
- They may need social skills interventions to help their self-esteem and better understand their actions and reactions

Adults interacting with these children need to know that:

- They are not “zoning out”
- The fatigue is real
- That they need to be sensitive to the child’s energy and stress levels
- Classroom assignments may need to be modified to accommodate the child’s endurance

- There may be times when memory and immediate informational processing (following directions) is significantly compromised
- These deficits often make these children emotionally vulnerable and at risk for low self-esteem
- Their skills may seem transient; being able to do something at one time and then not the next—these children cannot “do it when they want to”, there are times when they simply cannot.

Helping children learn to regulate their bodies, understand and anticipate their personal body cycles and rhythms is an essential element in helping all children interpret the world around them.

There is a lot we can learn from these children with mitochondrial disease. But perhaps the most basic lesson is that without the power to do, we have no power to grow; and we can only grow from what we learn to do.