Summary – Ideas from an Occupational Therapist
Susan Orloff

Focus on what we CAN do

Because Mitochondrial Disease is such a complex, complicated and diverse disease and because it is hard to diagnose, one of the most important roles a parent can play is to educate others (ie, teachers & therapists) about the disease. We must all also be hopeful when we discuss a child (or adult) with Mitochondrial Disease. For example, stating that 3-year-old Susan is happy, loves peanut butter, has a puppy and can count to 10, should preface the fact that she also has Mitochondrial Disease. In other words, stress the positive aspects of the person first.

The Role of the Occupational Therapist

In 1917 when soldiers returned from Word War I, many were injured and had to be retrained for new jobs; hence, the profession of occupational therapy was born. Curative workshops were held for this retraining and this is exactly what is still being done today. The OT's frame of reference is function, specifically in the areas of cognitive, neuromuscular, physical, sensory and emotional function. Using both research and evidenced-based practice, occupational therapy addresses these functional areas with meaningful activities. Assisting people to perform activities of daily living is one major aspect of this, and for children, going to school is an essential activity. Helping a parent set up a routine for their child to get dressed in the morning would be one example of an occupational therapist's role. Another might be to teach a child with visual field deficits to perform visual scanning.

Specific Strategies to Overcome the Many Challenges of Mitochondrial Disease

Conquer Ignorance

Parents may need to define the disease for teachers and others in simple language. "My child's internal energy factory is not producing the way it should; therefore, my child is more fragile than others." Don't get lost in complex language, just explain why your child gets tired more easily, cannot digest solid foods, etc. Use tools such as the Energy 4 Education DVD and daily checklists found in the School Advocacy section to help educators understand how to create strategies that are supportive to your child's unique needs.

Energy Conservation

Both in the classroom and in the workplace, this can be a challenge. If a child can demonstrate with 5 written answers that she knows the given material, then she should not have to write 10 answers. If an adult has to come to an early morning meeting several hours earlier than normal, then a request should be made for a longer lunch break. Such accommodations are available and provided for by law, but they do need to be requested. It's ok to let people know that you are simply having a bad day: "I'm having a Mito day today."

Strength & Endurance

Graded activities as noted above are important for children (and adults). Individuals need to be their own internal monitors of their physical rhythms - especially

disturbances in heart rhythms. Those with movement disorders also need to self-monitor, but for children we can begin to help by using things like pencil guards for a child with weak hand muscles. The key is to teach the individual to read their body and stop before they have reached their ultimate endurance level.

Fatigue can occur even when sitting for people with Mitochondrial Disease, so getting up and moving or changing position frequently is essential. Sitting backwards in a chair for part of the day can be useful for some children, as is the use of isometric chairs or "Back-Jack" floor chairs. Children can be encouraged to take a break in class and go sit on a bean bag chair for short periods of time. In all situations, every school system should have an occupational therapist at least as a consult to help set up these plans. This is the law, and parents may need to advocate for this if the school system does not have adequate professional help.

Reading Cues

For both parents of children with Mitochondrial Disease as well as adults with the disease, reading the body's cues as to when to stop an activity before "crashing", can be difficult. The key is to react and take action early - don't wait until symptoms are severe. For children, keeping track of whether their engine is running "high, medium or low" can be achieved with a pie plate-like chart. If two parts of the engine are on low - then don't wait - tell the teacher now and it is time for a break! Adults need to take the same inventory of their symptoms. Make a list and perhaps put it on their Blackberry or iPhone. Again, if two systems are running slow or if there are two symptoms, STOP! Essentially, we must learn to break down activities and symptoms into very small segments and pay close attention to them when they are "out of sync."

Comforting

When a crisis or crash does occur, it can be difficult to comfort a child (or adult). Using a blanket warmed in the dryer may help for someone with a tactile (touch) overload. Some children need to be sensitized to different sounds and may find loud noises, such as a fire alarm, very distressing. Other children have proprioreception (the sense of your body in space) issues, and as a result their whole body may be affected; play using the full body (such as making shadows move) may help here , and can be a source of fun for all the children in the classroom.

Achieving Balance

Achieving a balanced lifestyle without undue fatigue is a major goal for adults and children living with Mitochondrial Disease. Young children need to be told that their "energy factory" works slower than other children's and that every 20 minutes or so, they may have to take a break...even if the child looks "ok". Use the break time to rehydrate or eat a small snack. This is true for adults as well - yet adults will most likely need to monitor themselves. Those with fatty acid disorders need to keep away from fatty foods, but others may benefit from a low carb, high protein & high fat snack for energy. The process for changing carbohydrates into energy is more difficult for some patients with energy metabolism disorders.

Children on feeding tubes need to be able to socialize while other children are eating, so they may need help in devising activities appropriate to their situation. Remember, emotional and intellectual stress can cause fatigue as much as physical activities, so balance is important here too. Plan ahead and take control over the situations you are getting into - make some choices ahead of time of what you will do.

Support from occupational therapists like Susan Orloff can help those living with Mitochondrial Disease achieve more quality of life in their every day.