

# Summary - Getting Through the Day with Mito: Treatments, Supplements, and Humor

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Mitochondrial disease is a disorder of multi-system organ dysfunction (slide 4), and symptoms of each affected organ system must be treated, regardless of the underlying cause. Because so many systems may be affected, multiple specialists may be needed on an ongoing basis, which can be burdensome on patients and families.

Organ systems most affected by mitochondrial disease include central nervous system, muscles, cardiac system, gastrointestinal system, and kidneys. The “ripple effect,” when one system is affected, causing other systems to become more symptomatic, is commonly seen with Mito. For example, when suffering a bout of constipation, migraines or other Mito symptoms increase. Mito patients often have more sensitivity to drugs, drug reactions, and drug interactions, but physicians should weigh risks and benefits before excluding medications.

**Fatigue** is a hallmark symptom for Mito patients (slides 5-6). Interventions center around conservation of energy and planned rest periods throughout the day. School programming considerations include working within IEP or 504 plans to meet educational needs. Creative ideas include:

- Wheelchair use, if necessary, as a way to conserve energy. This step is difficult for children and teens who strive to be just like their peers.
- Rest in the nurse’s office or elsewhere, but use caution as nurse’s offices are often a hotbed for germs!
- Abbreviated gym class/gym class late in the day. Early gym classes may lead to poor attention due to fatigue in subsequent classes.
- Abbreviated school day, supplement with tutors as necessary.

Vacations, shopping, and office visits can increase fatigue, and patients should weigh the benefits of coupling multiple tasks in one day vs. limiting outings to one per day. Time of day is another consideration as some patients do well in the morning, but fade by afternoon, while others need time to wake up to be productive.

- Employment — Physician letter to the employer may help advocate for an employee to be more productive at work
  - Part-time employment may be best for some.
  - Alternate sitting and standing or offer brief rest periods.
  - FMLA — Family and Medical Leave Act entitles employees, when covered, to take unpaid, job-protected leave for medical reasons.
  - Consider CoQ10 — first-line supplement for mitochondrial disorders. Time medication doses to better cover activities with increased energy demand. Use reputable brand, backed by research for best quality.

- Carnitine — Mitochondrial Medicine Society did not include levo-carnitine in the consensus statement. Generic carnitine is also experiencing nationwide shortage at this time, but brand name and generic liquid are available. Timing of doses can help!
- PT referral — conditioned muscles use energy more efficiently. Activity is very individualized and may range from passive exercise (therapist moves limb/muscle groups) to light exercise, such as arm raises or walking in house, to more active exercise, like swimming or water classes, yoga, and more.
- Complementary therapies — massage, acupressure, acupuncture, Reiki, therapeutic humor.
- Decreasing carbohydrate intake and overall good nutrition can help with fatigue. For example, eating four candy bars is not ideal! Eating fruits and vegetables and getting the correct amount of protein when tolerated can have a significant impact on energy levels. Meet with a dietitian to create an individualized plan.

**Chronic pain** is another common symptom that can change personalities over time, create a big drain on a body's energy, and negatively impact quality of life (slide 7). Aggressively treating pain, therefore, is in the best interest of a patient with Mito. Pain is exacerbated in:

- Illness and/or trauma.
- Depression, anxiety, excitement, and any strong emotional state add to fatigue and pain. Chronic pain increases depression and anxiety rates.
- Traveling for short or long distances, or even to doctor's appointments. Respect individual limits.
- Changes of seasons and changes in weather patterns. Light box therapy is helpful for Seasonal Affective Disorder (SAD) with few side effects.

Medications are available to treat pain, although other options have been found to be as or more effective than many pain medications (see complementary therapies above).

**Therapeutic humor** added to each day promotes health and wellness. Scientific studies have demonstrated the positive effect of just 10 minutes of laughter per day. Norman Cousins, author of "Anatomy of an Illness," talks of his own illness and success with vitamin C and laughter. Day-to-day life with a chronic illness has unique challenges, but lives can be filled with special gifts as well.

### **Intake and Elimination** (slides 8-9)

Proper intake combats fatigue, therefore, children and adults should strive for adequate calories and fluid intake while also considering optimal types of fluids and foods. An easy indicator of hydration status is urine color, which should be very light yellow. Vitamins and medications can impact color, but noticing patterns offers insight to hydration status. Mito patients seem to do better with more fluids. Diluting Gatorade may be helpful, but water is optimal.

A dietary plan begins with assessing the ability to chew, swallow, and digest, as well as the energy demands of eating, especially in the pediatric population. A lower carbohydrate load coupled with good fats and appropriate levels of protein have proven effective for many Mito patients. For example, smoothies and soups with added oils are excellent ways to cover caloric requirements and get good fats and proteins in an easier to manage format. Supplements and the vitamin cocktail are individualized based on age, size, type of Mito, and previous response to therapy. Guidelines are available, but each patient should work closely with his team to develop a safe and effective medication plan. The response can take week to months.

Constipation and loose stools are another common problem for Mito patients. Laxatives may be necessary and many patients follow a maintenance bowel regimen, which includes adequate fluids, probiotics, foods to avoid or add (fiber), medications, and good nutrition.

### **Temperature Regulation** (slide 10)

Heat and cold intolerance stress the body and increase energy use, therefore, both shivering and overheating should be avoided. The baseline body temperature may be low and should be documented as such so that fever can be assessed more accurately. If a baseline body temperature is 95 degrees, a fever would be present at 98-99 degrees. When a baseline temperature is elevated in the absence of illness or other symptoms, a child may be able to safely stay at school as that child is not ill nor contagious. Consider:

- Air conditioning in classrooms, transportation, home.
- Cooling vest, scarf, and hat -- Be proactive to prevent issues!
- Layering of clothing.
- Restriction of outdoor activity in high heat and humidity and frigid weather.
- Referral to a dysautonomia specialist.

### **Environmental Hygiene** (slide 11)

Exposure to germs is high in schools and for day care and school staff. Repeated illness, coupled with longer recovery times, can weaken the immune system. To decrease viral load:

- Wipe down keyboards and shared equipment.
- Use separate school supplies when possible.
- Practice good hand washing.
- Use hand sanitizer for times when soap and water are not available.

Treating illness more aggressively is key as illness stresses the energy system. Being seen by the primary physician instead of taking the “wait and see” approach and having plans for vomiting, fever, and ER visits help the family know when to seek help (slide 12). Patients and their medical teams should expect some regression with strep, flu, high fevers, anesthesia, and surgical procedures. Adults may experience memory loss after a prolonged illness. Recovery phases after illness may exceed four weeks.

**Emotions**, including sadness, anger, or even excitement and joy, all cause a large energy drain on the body (slides 13-14). Treat depression and anxiety quickly. Talking out feelings and mindful meditation can be therapeutic as the attitude toward health and wellness has a documented impact on outcome. It's important for medical professionals, friends, and family to validate symptoms of the patient and family unit.

**Exercise** is recommended for Mito patients, but to varying degrees on an individual basis (slide 15). Even deconditioned patients are encouraged to exercise; a 20-year-old non-exerciser is less healthy than a 65-year-old who exercises.

- "If you don't use it, you lose it!"
- PT referral may be helpful after long periods of decreased activity or illness.
- Start small with arm lifts or stretches. The aim is not to run distances, but work the muscles to improve function.
- Never exercise in a fasting state and refuel within one hour of completion of exercise with protein and carbohydrate.
- Be considerate of those with exercise intolerance.
- Exercise in general improves quality of life in Mito patients.

### **Be Proactive!** (slide 16)

"Sweat the small stuff!" as it can quickly become BIG stuff!

- Evaluate for treatable illness
- *Under Medical supervision consider:*
- Alpha-lipoic acid, vitamin C, etc.
- Check Vitamin D and Ferritin levels, especially with fatigue.
- Consider Magnesium for muscle pain and constipation.
- Consider Creatine for energy boost.
- Flu vaccine as appropriate.

Specialties and Subspecialties that may be needed, based on clinical symptoms and presentation (slide 17):

- Sleep Study
- Cardiology
- Nutrition/dietitian
- Pulmonary
- Ophthalmology/Optometry
- ENT/Audiology Evaluation
- PT, OT, and Speech Therapy
- Chiropractor, Massage, Energy work
- Endocrinology
- Rheumatology
- Palliative Care - may be useful for pain
- Counseling/Psychiatry

**Summary** — No two patients are alike; therefore no two treatments and therapies will be the same!

- DO NO HARM.
- Quality of life issues, including the ability to perform activities of daily living should be addressed.
- Mito does not define the person, rather, the person is affected by the dysfunction.
- Community specialists do not need to be experts in Mito, but should understand the disorder and be willing to work with the patient and other providers to provide optimal care for the patient.
- Medical marijuana/Marinol use for Mito patients -- laws vary state to state.