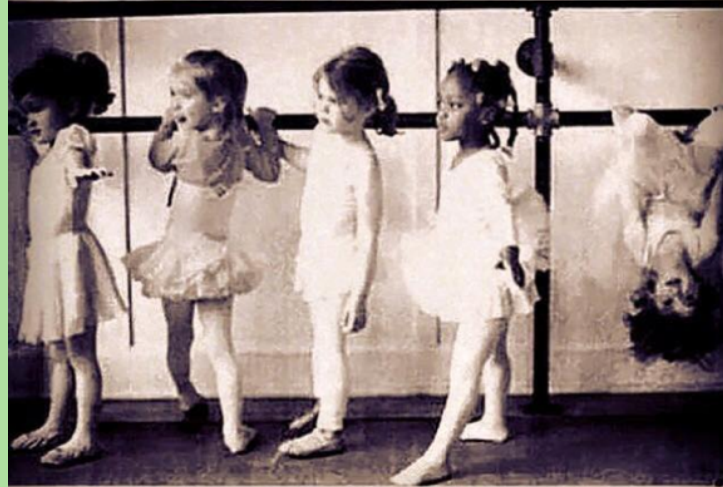


GETTING THROUGH THE DAY WITH MITO: Treatments, Supplements and Humor



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Be the girl on the right



PATIENT CARE CONSIDERATIONS

- Disorder of Multi-System Organ Dysfunction
- Fatigue
- Chronic pain
- Intake/Elimination
- Temperature regulation
- Environmental hygiene
- Illness
- Emotions
- Exercise



Disorder of Multi-System Organ Dysfunction

- Treat symptoms of affected organ system
- Organ systems most affected by mitochondrial disease
 - CNS, Muscles, Cardiac, GI system, Kidneys
 - Sensitivity to drugs/reactions/ drug interactions – in some cases there are many providers prescribing medications that may interact
 - Risk vs. Benefit ie. Depakote
- Ripple Effect
 - One affected system: Increased “MITO” symptoms throughout
ie. Constipation, Headache, Fatigue, Dysautonomia symptoms



Fatigue

- Planned rest periods
 - School programming considerations
 - Wheelchair if necessary
 - Resting in nurse's office
 - Abbreviated gym class (later in day)
 - Abbreviated school day, tutor as necessary
 - Vacations, shopping, office visits
 - All in one day or separate
 - Work days – employment part-time, alternate sitting w/ standing, FMLA



Fatigue

- Consider Co Q 10 or Carnitine dose time change
 - Activities with increased energy demand
- PT referral
 - Conditioned muscle more efficient energy usage
- Complementary therapies
 - Massage, Acupressure, Acupuncture, Reiki/Therapeutic Humor
- Decrease carbohydrate intake vs. good nutrition



Chronic Pain

- Exacerbated States
 - Illness, Trauma
 - Depression, anxiety, excitement
 - Traveling
 - short or long distances, MD appointments
 - Change of seasons
 - Light box?
- Treat “aggressively”
 - Energy expenditure with pain
 - Consider medication used with Fibromyalgia if appropriate
 - Therapeutic Humor – promotes health and wellness



Intake

- Adequate fluids and calories
 - Children and Adults
- Type of fluids and calories
 - Carbohydrate vs. Protein vs. Fat
- Ability to chew/swallow/digest
 - Follow healthy diet, processed food intake – solids vs. smoothies, small frequent meals/snacks
- Supplements/ Vitamin Cocktail
 - individualized “cocktail” for each patient – general guidelines are available
 - be aware of differences among brands when using OTC



Elimination

- Chronic constipation common
 - Consider as needed laxative
 - Maintenance bowel regimen
 - Adequate fluids
 - Probiotics
- Loose stools
 - Carbohydrate adjustment may be helpful
 - Probiotics



Temperature Regulation

- Heat/Cold intolerance
 - Prevent/minimize shivering and overheating
 - Baseline body temperature may be low
- Considerations
 - Air conditioning in classrooms & transportation
 - Cooling vest, scarf and hat
 - Consider restricting outdoor activity in high heat & humidity
- Consider referral to Dysautonomia Specialist



Environmental Hygiene

- Decrease viral load
 - Wipe down keyboards
 - Wipe down shared equipment
 - Recommend separate school supplies when possible
- Hand washing
- Hand sanitizer
 - Carry in backpack, purse, glovebox



Illness

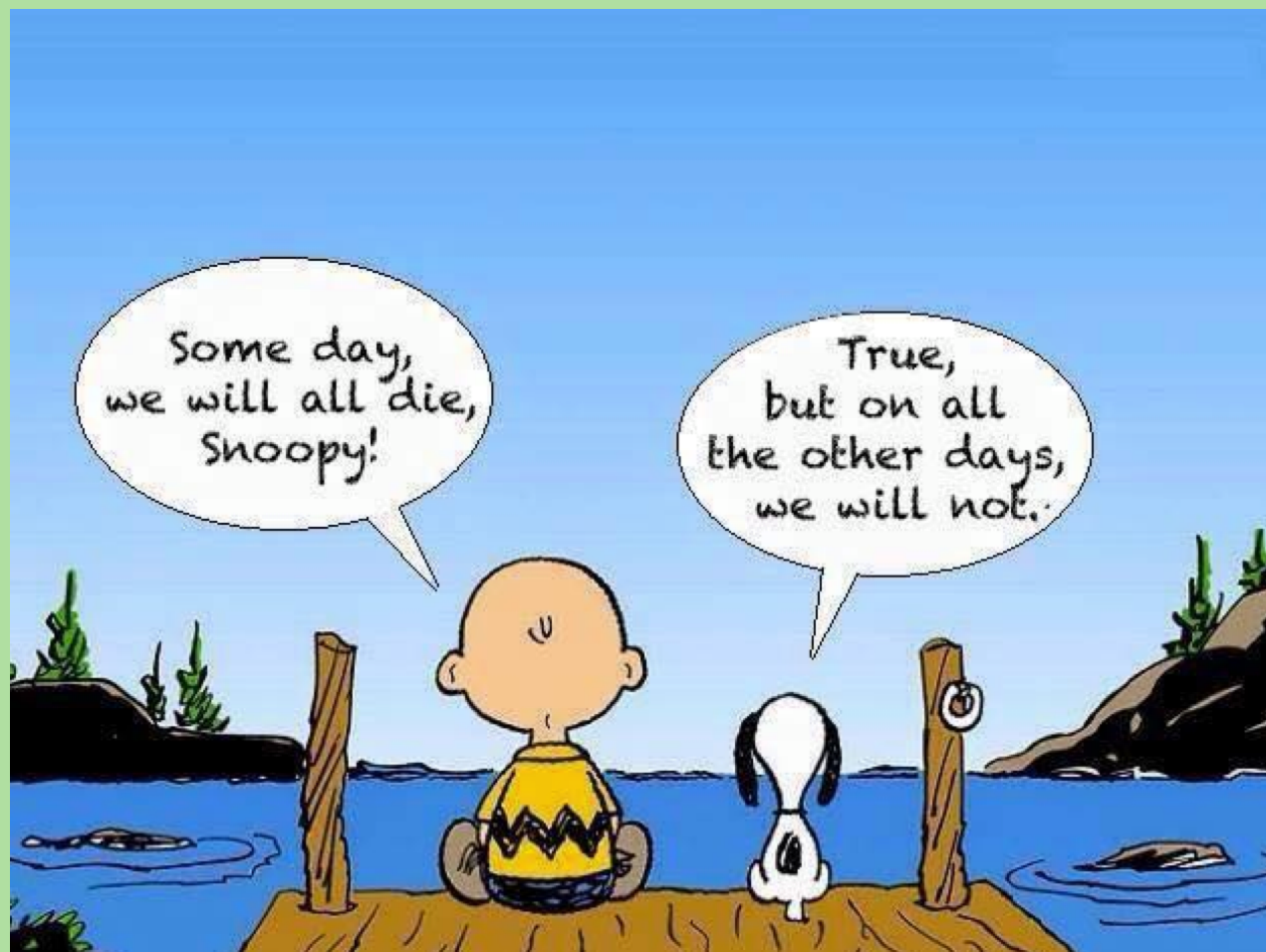
- Treat aggressively
 - Evaluate in person, do not “wait and see”
- Possible regression in children with Strep, Flu, High Fever, Anesthesia/surgical procedure
- Frequent memory loss in adults after illness
- Prolonged recovery phase
 - Not uncommon to exceed 4 weeks recovery time
- Consider PT after recovery



Emotions

- Large energy usage
 - Happy, sad, angry, ecstatic
- Treat anxiety and depression quickly
 - Consider anti-anxiety and other medication as necessary
- Stress
 - Consider counseling/talk therapy, mindful meditation
- Important: validate symptoms of patient and family





Some day,
we will all die,
Snoopy!

True,
but on all
the other days,
we will not.

Exercise

- Recommended – “If you don’t use it, you lose it”
 - PT referral may be helpful if long period of decreased activity
 - Even a deconditioned patient should be encouraged to exercise – a 20 yr. old non-exerciser (sedentary) is less healthy than a 65 yr. old who exercises
 - Endurance exercise vs. resistance training
 - Never exercise in a fasting state – snack within 1 hr. of completion of exercise – protein and carbohydrate
 - Be considerate of pts with exercise intolerance
 - Exercise in general improves quality of life in Mito patients

Be Proactive!

- “Sweat the small stuff”
 - Evaluate for treatable illness
 - Consider Alpha-lipoic acid, Vitamin C, etc.
 - Check Vitamin D and Ferritin level – especially with fatigue
 - Consider Magnesium for muscle pain & constipation
 - Consider use of Creatine for energy boost
 - Flu vaccine as appropriate

SMALL STUFF CAN QUICKLY BECOME BIG STUFF!



Specialties and Subspecialties

- Consider referrals for:
 - Sleep study
 - Cardiology – EKG, Echo
 - Nutrition/dietitian evaluation
 - Pulmonary/Pulmonary Function Testing
 - Ophthalmology/Optomtry
 - ENT/Audiology evaluation
 - Physical/Occupational/Speech Therapy
 - Chiropractor/Massage/Energy Work
 - Endocrinology
 - Rheumatology
 - Palliative Care
 - Counseling/Psychiatry

Things to think about...

- No two patients are alike, therefore no two treatments/therapies will be the same
- DO NO HARM
- Quality of life issues – ability to perform activities of daily living
- Mito does not define the person – they are affected by the dysfunction
- Community specialist – does not need to be an “expert” in Mito – should have an understanding of the disorder and a willingness to work with the patient, find out more and work with the team/other specialists to provide care for the patient
- Medical Marijuana/Marinol – use in Mito?