



Support, Educate, Advocate

Mitochondrial Disease Action Committee

Daily Health Assessment Form

1. Liquid Intake. _(_____)liquid intake must be monitored by an adult at all times. An adult must insure that her thermos is with him/her at all times, and must remind he/she to drink from it regularly.

While in school, _____ must consume between __ and __ ounces of liquid including the liquid she consumes during lunch. The amount of liquid consumed must be monitored, documented in writing concurrently with intake and reported daily to the parents.[1] (Parents will send /him her with an 8 oz. thermos, and with the liquids.) He/She must drink throughout the day, approximately __ ounces or less at a time. He/She must be monitored to make sure he /she does not drink more than __ ounces at one time, because this can cause stomach upset and bladder spasming. He/She should wait at least 45 minutes between liquid intakes of __ ounces.

Parents should be contacted immediately if:

- _____ Within 45 minutes of consuming __ ounces of liquid he/she asks for more to drink, or
- _____ Within 45 minutes of consuming __ ounces, he/she says she is still thirsty, or
- _____ If _____ asks to drink more than __ ounces during the school day.

Such notice to parents is essential as continued thirst can be a symptom of other medical problems.

2. Solid Intake. In order to keep his/her metabolism at an appropriate level avoid energy loss, and reduce the risk of fatigue, _____ must eat multiple small meals throughout the day, as follows:

- a snack at 8:30 a.m.,
- a snack at 10:30 a.m.,
- her lunch at lunchtime,
- a snack at 12:30 p.m. and
- a snack at 1:30 p.m.[2]

Parents should provide pre-measured quantities of snacks, each separately wrapped. The snacks need not be eaten in a particular order, and _____ should be allowed to choose the order. However, _____ should consume the entire contents of a particular snack at each intake session, unless she indicates that he/she is not feeling well enough to eat the snack. In this case, he/she should be taken to the nurse's office immediately, and the parents should be contacted.

Because of his/her digestive difficulties he/she should not be required to eat the snacks quickly, as doing so can cause severe abdominal discomfort and can result in improper digestion, depriving her of the nutritional value of the snack. Thus he/she should be allowed to eat the snacks slowly in his/her classrooms at the assigned times, rather than between classes or at his/her locker.

The amount he/she consumes at each snack session and the time of consumption must be monitored, documented in writing concurrently with intake and reported to the parents. Any snack that is uneaten at the end of the school day should be sent home rather than discarded, so that the parents can fully monitor all food intake. Any uneaten portion of his/her lunch should similarly be sent home.

3. Protocol re events requiring immediate trip to school nurse.

A. _____ must be aided in going to the nurse's office and seeing the nurse IMMEDIATELY when he/she asks to see the nurse. NO DELAY is acceptable.

B. _____ must be monitored diligently while working in class and throughout the school day for signs of any of the following, and if they appear, he/she must be brought immediately to the nurse's office and the parents must be contacted:

- unusual pallor, paleness
- flushing (redness)
- inability to regain focus visually
- fatiguing
- cramping (hands, limbs, abdominal, other)
- increased or decreased body temperature (below or above)

- disorientation
- chest pain
- irregular heartbeat - - tachycardia, bradycardia, or V-tach (fast, slow or skipped)

(Note: _____ will tell an adult if he/she feels fast, slow or skipped heartbeat.)

- dizziness
- shaking/trembling
- difficulty breathing/swallowing
- headaches
- _____ stating he/she does not feel well enough to finish a scheduled snack

Further protocol re above symptoms:

If signs of any of the above appear, or if _____ complains of any of the above, adult must immediately proceed with him/her to the nurse's office and parents must be contacted immediately.

Parents must be contacted immediately if/when body temperature is above 98.6 or if it is below _____ ; _____ core body temperature is _____ which means _____ is considered a fever. (Note - we need to clarify high and low temperatures above.)

In the event of difficulty breathing, the nurse is to administer prescription _____ inhaler as prescribed.

In the event of chest pain or difficulty breathing, nurse/school are to contact parents immediately, even if the episode is brought under control.

C. Further protocols re fatigue. If _____ complains of fatigue, he/she must be brought to the nurse's office and allowed to nap or rest for up to 30 minutes. If _____ says he/she is ready to return to class before 30 minutes is up, he/she should do so. The time and duration of such rests and naps should be monitored, documented in writing and reported to the parents. _____ should not be left without adult supervision when in the nurse's office.

D. Protocols re visual fatigue. If _____ complains of visual fatigue, the adult monitoring her must evaluate whether or not he/she can quickly regain focus (for example by blinking a few times). If he/she cannot regain focus quickly, he/she must be brought to the nurse's office. If he/she can regain focus, but has visual fatigue, the adult monitoring her must take over for _____ by taking class notes either by hand or by using _____ laptop.

E. Adult to accompany (child's name) to nurse's office. _____ must be accompanied by an adult when he/she goes to the nurse's office for his/her afternoon medications, due to the risk of cramping, falling and/or becoming disoriented.

F. Administration of Co-enzyme Q10. _____ must be given 200mg. of Co-enzyme Q10 at lunchtime by the school nurse only.

G. Notice to parents of all medications administered. Nurse must inform parents daily in writing of all medication administered to _____.

4. Protocols re traveling in building and carrying items.

A. Adult supervision at all times. Due to his/her physical weakness and propensity to fatigue, it is unsafe for _____ to be without adult supervision at any time. _____ must not be left unattended at any point during the school day to ensure his/her safety. He/She must not be placed in the hallway or other locations unattended.

B. Carrying books, supplies, other items. _____ must be assisted whenever he/she transitions between classes or otherwise travels in the school, by having an adult carry any and all materials, including backpack, laptop, snacks, liquids, papers and other school needs. This is necessary to prevent energy depletion and to reduce the frequency of cramping and spasming and the risk of falling due to muscle fatigue.

C. Adult to accompany (child's name) to nurse's office.
As noted above, _____ must be accompanied by an adult when he/she goes to the nurse's office, whether due to symptoms or for his/her afternoon medications, due to the risk of cramping, falling and/or becoming disoriented.

D. Stairs and elevators. While _____ can presently navigate stairs provided that an adult is accompanying him/her at all times, it would be preferable for his/her to use an elevator, both for safety reasons (risk of falling) and to conserve his/her energy.

5. Protocols within classrooms, in preparation for classes and preparing to go home.

A. Room temperature. Because of body temperature dysregulation, the ambient room temperature in his/her classrooms and in any location where he/she spends time must be no less than ___ and no more than ___ degrees.

B. Organizing materials throughout the school day. Because the effort of organizing his/her materials depletes _____ energy, and because _____ short-term memory decreases throughout the day rendering he/her less able to remember the materials he/she needs, the adult supporting _____ must assist in such organization by making sure that the proper books, papers and other supplies for each class are brought to that class and are organized for use during class. In addition, the adult must transport _____ snacks and fluids and make sure that they are within his/her reach throughout the school day. In addition the adult must make sure that the materials _____ needs for homework are in his/her backpack at end of the school day.

C. Monitoring hand fatigue, handwriting, use of laptop. An adult must monitor _____ to note when he/she is unable to use the laptop or when his/her handwriting becomes illegible. This can be due to fatigue, visual difficulties or cramping. In all such cases, the adult must take notes for _____, either by hand or by using _____ laptop. It is important for the adult to be aware that _____ may not realize that his/her handwriting has become illegible.

D. Reinforcement and support of academic learning during class. _____ needs an adult in all his/her classrooms to verbally repeat and rephrase directions to his/her and to provide his/her with additional visual supports to include three- dimensional items when possible to reinforce and

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insure his/her comprehension at the time of instruction

E. Monitoring for memory lapses, inability to retain information.
An adult must monitor _____ for any lapses of memory or inability to retain information, document such lapses and inability in writing, and inform the parents daily of any such lapses or inability.

F. Written information re classroom instruction occurring when (child's name) is not in class. When _____ is at the nurse's office, or when he/she is ill, an adult must provide notes of class lectures, activities and assignments for _____ later use.

6. Stress reduction. _____ experiences stress in connection with him/her effort to cope with the symptoms of him/her disease, and this stress can in turn cause further fatigue and potential progression in him/her disease. He/She should be assisted in reducing stress levels by providing the specific supports described above and by maintaining an encouraging attitude toward he/her.

As these protocols are necessary to ensure _____ medical well being these measures must be taken daily without exception.

_____, M.D.

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Primary Care Physician for _____

[1] Parents need daily report on amount of liquid intake at school in order to monitor and insure appropriate total daily liquid intake.

[2] Snacks in the afternoon must be closer together because his/her energy level falls in the afternoon