

Mitochondrial Disease/ Debilitating Fatigue/ School¹

_____ is a ____th grade student at _____ (school name). She/he is diagnosed with Mitochondrial Disease which often causes debilitating fatigue. _____ has been home tutored and or supported by his/her school district for the majority of _____ grades and attended school very intermittently when his/her health allowed him/her to participate either socially and/or academically. _____ displays a combination of cognitive, neurological, and physical symptoms, coupled with the unpredictability of symptom presentation and illness course. Symptoms will wax and wane on a daily, sometimes hourly basis. Therefore, it is not uncommon for _____ to display fluctuating cognitive abilities, short-term memory deficits, variability in concentration or difficulty with reading and writing. Cognitive activities, at times, may be more fatiguing than physical exertion. Instruction must take into account this unpredictability and maximize the often small windows of opportunity to present material.

_____ has never been able to attend school on a normal schedule and has gone from 1-3 hours a day in the first grade to an hour a day in the fall and the late spring in 5th and 6th grade. She/he often has had to come in a wheelchair or with crutches due to extreme leg pain and weakness. The school has provided a home tutor since the first grade.

_____ 's health is at its best in the early fall and very late spring. At these times She/he can manage 2 hours a day of tutoring and possibly some time in school. In the late fall through the winter even tutoring can be a struggle and sessions may vary in length along with her/his abilities.

"Good Days" vs. "Bad Days"

On "Good Days" _____ is able to concentrate, produce written work and be extremely productive in completing his/her lessons in Math, Language Arts, Science or Social Studies. This may include doing Reading and answering questions, or completing lessons in Math or grammar. On a good day She/he can work for 2- 2 ½ hours with one on one instruction (semi-reclined on the sofa for 90% of the time).

On a typical "Bad Day" the session may be cut short due to the onset of severe migraine type headaches, severe chest pain and overall body weakness and pain. On these days, _____ is unable to sit up and is unable to walk on her/his own, and must navigate the rooms in the house using her/his wheelchair. She/he suffers from periods of light-headedness, dizziness, blurred vision and fainting in conjunction with the other symptoms of pain previously mentioned. On a really bad day _____ may be unable to do any work and tutoring is canceled, but this is kept to a rare instance.

Communication between Tutor and Teachers

The home tutor will be supplied with her/his own set of textbooks, teacher's manuals and course syllabus and course goals and objectives for the entire school year. The tutor will consolidate assignments with the teacher's assistance and hand assignments/tests in as they are completed for the teacher to grade. A box will be placed in the Special Education Teacher's Room with _____ 's name on it for work and material to be dropped off and/or picked up by the tutor.

Role of the Teacher

The Classroom teacher will be responsible for:

- Providing the tutor with weekly lesson plans
- Providing the tutor with class handouts/notes

- Providing the tutor with assignments/projects/quizzes
- Communicating with the tutor about the priority work that needs to be completed within the minimum course requirements.
- Providing the tutor with Chapter/ Unit Tests (at the beginning of unit if possible)
- Contacting the parent and/or tutor with concerns about _____'s work/ progress
- Grading assignments in conjunction with the tutor's assessment (based on minimum course requirements and completed assignments)
- Meeting with the tutor to discuss _____'s work each quarter and assign a grade
- Recording a grade for each quarter on the report card

Role of the Tutor

The home tutor will be responsible for:

- Providing one-on-one instruction in the home environment
- Implementing a variety of teaching strategies to maximize _____'s learning
- Communicating weekly with the special education teacher Liaison
- Communicate with teachers as needed to clarify assignments/ assess work
- Meet at the end of each quarter as needed with the teachers to discuss _____'s progress and to offer input on a grade for the quarter

The tutor begins each day with an assessment (a combined observation by the tutor and communication with the student) of _____'s condition and durability. Decisions are then made to prioritize instructional alternatives and individualize methodology. Tutor/student communication is essential throughout each session. It is not unusual to have to switch gears if _____'s symptom's change or intensify.

Helpful Accommodations Include:

- Allowing _____ to lie down or keep her/his feet elevated for her/his lessons
- Allowing _____ to take short breaks and/or take her/his pain medication (dispensed by _____)
- Acting as a scribe
- Copying pages from the books and highlighting material instead of writing answers (esp. useful in Lang. Arts grammar and short answer questions in content areas)
- Using dry erase board to take notes and do math problems. The tutor often then copies the notes into a notebook.
- Modifying the curriculum to accommodate _____'s learning difficulties and yet maximize both the quantity and the quality of her/his learning.
- The freedom to teach units in 1-2 subject areas at a time and rotating areas of emphasis. (For one to two weeks lessons may concentrate on Science and a bit of Math, and the following few weeks on Social Studies and a little Language Arts.) In the course of a 10 -week grading period all subjects are attempted but they are not all taught every week.
- Condense material
- Extended time for tests

While it is the tutor's goal to make measurable progress in each subject area during each quarter, in reality _____ cannot be expected to track his/her classmates in all of the work. It is important to look at _____'s overall progress when assessing her/his work each quarter.

Information for this template was gathered from:

1. <http://www.pediatricnetwork.org/>