

My child with Mito needs an aide, how do I obtain one?

Here is a sample "life event" template. It is often easier to convey your child's needs to school staff when they understand how your child is affected by his or her mitochondrial disease/disorder. Use this ONLY as a template by inserting your child's name and gender. This document has helped many parents convey the complexities of educating their child with mitochondrial disease, as well as supporting the need for a personal aide. When an educator poses the question such as, "Why does Johnny need an aide?" Use these simple examples, if applicable to your child to help you explain and educate your educators.

Medical Support Reasons for an Aide

1. Aid in making sure proper drinking and eating are taking place for optimum energy levels.

LIFE EVENT: () becomes light headed, vision blurs, and fainting occurs when dehydration and hypoglycemia occur due to lack of nutrition and fluids. On average we have between () to () events monthly with close monitoring.

2. Monitor pallor for signs of dehydration

LIFE EVENT: Missed signs of loss of color have led to fainting spells and bath immersions to cool his/her body temperatures as he/she cannot regulate his/her body temperature himself/herself. He/She can be completely inactive and dehydrate. Activity does not have to exacerbate an episode.() also has extreme difficulty with cold. We keep him/her dressed and then he/she gets in the tub of warm water. If we undress him/her before he/she becomes so chilled that his/her lips turn blue and he/she feels lightheaded.

3. Monitor () inability to ask for medical intervention when he/she cannot.

LIFE EVENT: () often loses her/his perceptions of time of day, not knowing if she/he has eaten, increased short term memory issues with fatigue. () often does not recognize that if he/she just eats something or drinks something that he/she will gain a little energy. She/He often awakes at night readying for school and it is 3:00am, he/she will not always UNDERSTAND that he/she needs medical attention. He/She will often show disoriented but not necessarily understand that he/she is becoming possibly critically ill.

4. Monitor and aid () in transitioning from classrooms and floors as the schools elevator is not working, still to continue when elevator is working.

LIFE EVENT: () daily loses his/her balance, new muscle disuse atrophying causes his/her limbs to give way without notice to cramping. He/She falls without notice, loses his/her balance because of poor muscle support. We at home assist him/her to make sure he/she navigates the stairs in our home. We have a shower seat so that he/she does not stand in the shower because he/she has fallen before. Although he/she could ride a bike finally last summer, she is not riding this summer or fall due to balance, endurance and strength issues.

5. Monitor and aid () when his/her vision changes, recognize that () is having difficulty seeing and enlarging or magnifying the information which is necessary for him/her to see. (I.e. focusing, blurred vision, floaters, peripheral vision, and eye fatigue)

LIFE EVENT: () suffers from migraines due to eye strain; he/she has extreme eye sensitivity as we all as transitional lenses to protect his/her eyes from bright lights. He/She often cannot focus, or has floaters which interfere with his/her reading and we read to his/her. We have purchased special computer software and equipment that magnify his/her at home work station to reduce eye strain as well as enlarge all his/her mapping assignments and other visual aids to sizes he/she can handle. We have also purchased special lighting to soften glare issues. He/She also has 8X10 magnifying sheets to enable quick enlargement of items.

6. Monitor and aid him/her to nurse's office for immediate medical assistance.

LIFE EVENT: We have had unattended fainting spells in school as well as in transitioning throughout daily life. We cannot always tell when he/she is going to be lightheaded, sometimes not until we hear the thud. He/She has a bell that she can ring at night in the event that he/she cannot get out and get us but feels ill.

7. Monitor and aid him/her in carrying ALL school materials for each class to reduce chances of fatiguing and cramping, spasming.

LIFE EVENT: In the event that () has to carry materials his/her hands spasm, his/her body fatigues quicker and he/she is more apt to fall. He/She falls often due to imbalances of carrying everyday items.

8. Monitor and aid () in arriving and leaving school while also packing his/her backpack with all the appropriate items that are needed to come home for assignments.

LIFE EVENT: Prior schooling peer support was attempted and it failed miserably. () is not able to recall even with visual aids that which he/she needs to take home. This in return causes HUGE issues in completing tasks and maintaining follow through and organization. Over () children attend her middle school, ages 11-15. It is imperative to note that he/she has already been knocked to his/ her knees and bumped into his/her locker during class changes. This is unacceptable.

9. Monitor and aid () in ensuring that she takes her afternoon medication.

LIFE EVENT: As () day progresses he/she is unable to maintain focus. His/Her fatigue causes /him/her to forget normal everyday things. Understand that if he/she has a night of poor sleep which happens often all of the above listed can happen when there is increased fatigue. He/She will forget to eat, dress appropriately, wash when she showers, remember important people and dates; we cannot ask him/her to remember to take his/her own meds at school. He/She can't remember short term multi tasks. For example bring your clothes upstairs, brush your teeth and comb hair. One will be accomplished never 2 or 3 and sometimes none. Sometimes he/she returns and says what am I supposed to do and other times he/she flat out just doesn't do or remember that he/she was even asked.

10. Monitor and aid () in recognizing that his/her endurance levels are dropping due to fatigue.

LIFE EVENT: We often have to stop () from continuing her studies or activities because he/she doesn't recognize that he/she is falling asleep mid act. We have come in and found him/her literally head on the table asleep amidst a task that he/she was enjoying.

11. Monitor and aid () in an attempt to reduce stresses which will cause physical discomfort, disorientation and involuntary progression of his/her disease.

LIFE EVENT: Be reducing stresses, hiring limousines to distract him/her from long rides to specialists, aiding his/her to recognize that he/she just needs to rest awhile. Navigating transitions, organizing his/her room and keeping consistent patterns in his/her daily life, managing his/her daily skills with sticky note reminders throughout the house, using skills that are mathematical skills such as cooking and correlating his/her academics into fun activities. Anything that reduces stress saves energy. We carry everything for him/her. Recently in Disney we rented strollers to save energy, without the use of a stroller and special pass which gave us immediate access to the events () would have never made Disney. Even with all these supports in place 3 days of a 10 day vacation were spent as off days so that he/she could regroup and sleep to make sure we weren't opening him/her up possible virus and or infections. Weeks of preparation go into his/her appointments, both medical and supportive. Making sure they are in the morning, making sure that no sleep overs, or events are taking place at minimum at least 3 days prior to ensure best testing and sleep patterns. In the event that his/her patterns of sleep are off we will reschedule his/her so that she can be tested at her best.

Educational Support Reasons for an Aide

1. Monitor and aid () in taking classroom notes when he/she is physically unable to do so.

LIFE EVENT: In past when () was healthier we spent hours deciphering notes, we spent hours on phones with other parents confirming assignments, we spent hours weekly returning to school for aid in understanding what was expected of () because we could not read /his/her writing. His/her hands cramp and spasm horribly at night from use, organizationally he/she was a disaster as nothing was legible.

2. Monitor and aid () to new tools of usage for writing in the event that he/she cannot write to use her laptop.

() often does not recognize the symptoms of his/her limbs hurting as being the reasons that he/she is distracted. Often times he/she would just write anything to show an attempt although it was completely inappropriate. I have many examples of his/her work showing this action. His/her hands cramp less when he/she types. Her thought processes are more complete when he/she types because he/she is not spending so much time on trying to get muscles to work through pain and is able to concentrate on the writing assignment before her.

3. Monitor her classroom subjects when he/she is resting or ill, ensuring that () receives all necessary materials to maintain his/her studies.

LIFE EVENT: () absences put him/her at a huge disadvantage. His/her inability to catch up due to extra exertion when /he she has been ill or recently recovering lead him/her to levels of stress that cause him/her to become irritable, frustrated, and create an environment of low self esteem.

4. Monitor and check written materials for clarity.

LIFE EVENT: Mentioned previously.

5. Monitor and verbally reiterate directions for clarity at the time of instruction.

LIFE EVENT: () retains more information when he/she is taught orally with visual aids as an adjunct. His/her testing shows that if he/she has an image to attach too although his/her recall is impaired he/she will do better having a visual to stimulate the response. For example, math, measuring and fractions. He/She cannot spatially understand $\frac{3}{4}$ of a cup in a picture. But show him/her a measuring cup and say fill it $\frac{3}{4}$ of the way he/she retains the information longer. Her memory retains more if he/she can hear and visually attach a mnemonic and a visual. His/her retrieval is also improved.

6. Monitor and reiterate verbal/visual manipulative at the time of instruction

LIFE EVENT: see previous answer.

7. Monitor and inform classroom teachers of inability and the need of time extensions for testing, quizzing or homework.

LIFE EVENT: () has often been tested at his/her worst times of day. IF you ask he/her she will tell you "yeah I can do it" because he/she doesn't want to let you down, but in all honesty he/she doesn't have the focus or ability to complete the task. Extra time is an absolute necessity, given verbal cues, and recognizing that he/she can learn the material if it is taught at prime times is huge.

8. Monitor and organize his/her needed books, notebooks and school supplies for upcoming class.

LIFE EVENT: As mentioned before if he/she has to take the time to organize his/her own materials due to memory issues he/she becomes frustrated and therefore physically starts to feel ill. He/She emotionally can fall apart if he/she feels he/she is not maintaining organization. He/She is completely disorganized at home without 24/7 support. He/She doesn't remember where things go unless we remind him/her. We are constantly not changing things within his/her room because repetition and placement of items keep him/her more on task. God forbid we put her/his bathrobe in the bedroom she/he would not know where to begin to look for it and if we are lucky she/he will remember to ask for it when and if she/he gut's cold, but even then there are times she/he won't.