

“Mommies Can’t Get Sick!”

Having a child with a chronic illness like Mito is extremely stressful for the child’s family. When a parent is also battling chronic illness, life instantly becomes much more tenuous. Due to the number of ways Mito can be passed from parent to child, you are likely to find children whose siblings, parents, or extended families are also living with the disease.

How does a parent’s illness affect their role in the family?

How can we support the child, support Mom, and support the family?

How many children with Mito have another family with the same mtDNA or nDNA defect? We don’t know for sure. There are many reasons for this:

- Mito is frequently misdiagnosed, especially in adults.
 - “Any disease. Any organ. Any age.” This is perhaps the best general summary of the spectrum of mitochondrial disease available (Christodoulou 1999). Mitochondrial diseases are notorious masqueraders (Kerr 1998). They can cause symptoms that are indistinguishable from those caused by common disorders (Naviaux 2000).
 - Children may share the same genetic mutation as a family member but display entirely different symptoms.
 - Video presentation by Dr. Mark Korson (Tufts Medical Center: The Floating Hospital for Children): He talks specifically about the challenges adults face when seeking a diagnosis and subsequent treatment: <http://www.youtube.com/watch?v=-zf3eYRGpk>
- Mitochondrial dysfunction can result from primary genetic defects, or as a secondary adverse effect of certain medications. Some of the more common “Mito-toxic” drugs include
 - Cholesterol-lowering drugs in the “statin” family
 - Chemotherapy agents
 - HIV medication
 - Aminoglycoside antibiotics are well-known for their nephrotoxic and ototoxic effects. Individuals with certain mtDNA mutations are extremely susceptible to these effects and can sustain permanent damage. The severity of the toxic effects may be disproportionate to the dose and length of administration

- A comprehensive list of drugs known to be toxic to mitochondria can be found here: <http://psychrights.org/research/Digest/NLPs/DrugsCauseMitochondrialDamage.pdf>
- DISCLAIMER: Patients and family members must discuss the benefit and risks of every medication taken with their own health care providers. Drugs with potential mitochondrial toxicity are used to treat life-threatening conditions. All medications are ordered and administered with a level of calculated risk. The parent or caregiver's role is to administer the drug precisely as directed, monitor for effective treatment, and report side effects.
- Gentamycin Toxicity: <http://www.dizziness-anbalance.com/disorders/bilat/gentamicin%20toxicity.htm>
- Mitochondrial disease has been identified as factors in many common illnesses, disabilities, and occurrences, but is rarely diagnosed as such.
 - Refer to: "Mitochondrial Disease in Adults"
- The origins of mitochondrial DNA defects and their impact on health and development is a new area of genetic and metabolic study ("our families as pioneers" frame).

Bowen Family Systems Theory <http://www.thebowencenter.org/pages/theory.html>

Bowen family systems theory is a theory of human behavior that views the family as an emotional unit; the family exists because of its intense emotional connection. Family members profoundly affect each other's thoughts, feelings, and actions; it is as if all live beneath a single "emotional skin." Any change in one person's functioning is predictably followed by reciprocal changes in the functioning of others.

The Wellness Inventory John W. Travis <http://www.wellpeople.com/>

- The Illness-Wellness Continuum: Illness and wellness are dynamic, not static states. It also suggests that "wellness" is not simply the absence of disease, and "illness" is not simply the presence of it.
- The Iceberg Model of Health: Illness and health are only the tip of an iceberg. To understand their causes, you must look below the surface. Only one-tenth of the mass of an iceberg is visible on the surface. The layers Travis applies to the "Illness Iceberg" include:
 - State of Health
 - Lifestyle/Behavioral Level
 - Psychological/Motivational Level
 - Spiritual/Being/Meaning Realm

- We are all Energy Transformers, connected with the whole universe. All our life processes, including illness, depend on how we manage energy.
 - Input: what we take in, from oxygen to food to emotional support to physical assistance. Are we taking in enough? Too little? Too much? Many moms hesitate to accept services because they fear they might be “taking them away from someone who needs them.” How can we demonstrate to parents that accepting help for themselves benefits their entire family?
 - Channel: the vessel where the energy exchange takes place. The size and condition of the channel, or reservoir, determines how much will be able to flow through. Is the channel able to handle the amount and type of input that is being provided? For example: Mom expresses an interest in becoming more organized. The Service Coordinator compiles a stack of pamphlets and books that outline organization methods, filing systems, and personal accounts of people praising the positive changes in their lives that occurred when they were able to achieve a higher level of organization. Mom thanks you graciously and sincerely as she sets the pile on the kitchen counter, where it remains for the next month, gradually disappearing under piles of other accumulating papers. What went wrong? What are some possible strategies to learn more about what the family needs to be able to use the assistance and guidance we are providing?
 - Output: our contribution to our family, community, the world. This includes all types of contributions; negative, positive, physical, emotional, intellectual.

Resources for parents with disabilities or chronic illness

www.lookingglass.org The National Resource Center for People with Disabilities/ Through the Looking Glass

<http://www.autism-pdd.net/resources.html#posts> Resources for adults with disabilities, not limited to autism

www.wheelchairnet.org/WCN_living/parenting.html A link to many, many more websites useful to parents with all kinds of disabilities, some links for parents with “invisible illnesses/disabilities” as well

www.familyvillage.wisc.edu/general/parentswwdis.html A list of websites that have articles, resources, and social/emotional support for parents with a multitude of disabilities

www.disabledparents.net “the Internet’s one-stop resource for parents with disabilities”

www.cmrg.com Case Management Resource Guide Finding CM for chronic illness/disability

“Parents and Chronic Illness: Taking Care of Yourself and Your Child” <http://www.parents.com/parenting/better-parenting/advice/parents-and-chronic-illness/>

<http://psychcentral.com/blog/archives/2010/09/27/10-challenges-for-parents-with-chronic-illness/>

“Living With Invisible Illness”: resources compiled for readers of MitoAction’s “Cut The Red Tape!” column <http://www.mitoaction.org/red-tape/living-invisible-illness>

Books:

“Mommy Has To Stay In Bed”: http://www.amazon.com/Mommy-Has-Stay-Annette-Rivlin-Gutman/dp/141964775X/ref=cm_cr_pr_product_top an excellent children’s book pertaining to chronic illness, target age 4-8 but the great pictures and rhythm of the story would captivate even a younger child

If you need to be hospitalized: http://www.amazon.com/Playdate-Kids-Dakotas-Goes-Hospital/dp/1933721030/ref=pd_sim_b_3

"When Someone Has A Very Serious Illness": http://www.amazon.com/When-Someone-Very-Serious-Illness/dp/0962050245/ref=pd_sim_b_4

"Living Well With My Serious Illness": http://www.amazon.com/Living-Well-My-Serious-Illness/dp/1577491394/ref=pd_sim_b_33

"Little Tree; a Story for Children with Serious Medical Illness": http://www.amazon.com/Little-Tree-Children-Serious-Medical/dp/1591470420/ref=pd_sim_b_3

“A Train’s Rust, a Toymaker’s Love”: <http://inheritanceofhope.org/component/virtuemart/details/1/1/store/a-train%E2%80%99s-rust.-a-toy-maker%E2%80%99s-love.html>

Here are some books that you can read for ideas about discussing sensitive subjects with children; giving enough information to ease their imagination and worry, but not too much that could cause even more worrying and confusion.

"Cereal For Dinner; Strategies, Shortcuts, and Sanity for Moms Battling Illness": http://www.amazon.com/Cereal-Dinner-Strategies-Shortcuts-Battling/dp/B000GG4HYS/ref=sr_1_1?s=books&ie=UTF8&qid=1300868724&sr=1-1 This is the best book I have ever read, and I've reviewed dozens of books about chronic illness. This book should be on every chronically ill person's bookshelf whether they are parents or not.

“Consider It Pure Joy”: <http://inheritanceofhope.org/component/virtuemart/details/12/consider-it-pure-joy.html?pop=0>

"Raising an Emotionally Healthy Child when a Parent is Sick": http://www.amazon.com/Raising-Emotionally-Healthy-Harvard-Medical/dp/0071446818/ref=pd_sim_b_4

"Beyond Casseroles; 505 Ways to Encourage a Chronically Ill Friend http://www.amazon.com/Beyond-Casseroles-Chronically-Conquering-Confusions/dp/0971660069/ref=sr_1_6?s=books&ie=UTF8&qid=1300868554&sr=1-6

Additional Resources for Parents with Serious Illnesses

Inheritance of Hope www.inheritanceofhope.org: Emotional and spiritual support through once-in-a-lifetime retreats for families with a parent with a life-threatening or terminal illness

Mother's Living Stories <http://www.motherslivingstories.org> The Mothers' Living Stories Project (MLS) brings compassion, support in parenting, and dignity to mothers who have a life-threatening or chronic illness by helping them record life stories and personal legacies for their children and loved ones.

The Dream Foundation <http://www.thedreamfoundation.org> The Dream Foundation grants final wishes to adults suffering life-limiting illness. Its focus is on providing those at the end of life's journey with a sense of resolution and completion. The foundation provides a non-traditional, palliative form of healthcare. Although there is no cure for the catastrophic illnesses afflicting the lives of dream recipients, the foundation helps by improving the quality of their lives in a way that medicine cannot.

The Adult Wish Foundation <http://www.adultwishfoundation.org> The foundation's mission is "to grant reasonable wishes to adults, 18 and above, with life-threatening illnesses, while supporting surviving family members and to enrich their lives with respect, love, and hope."

The Liz Logelin Foundation <http://thelizlogelinfoundation.org> The Liz Logelin Foundation was established to assist families who find themselves in the heartbreaking, catastrophic situation of having lost a spouse, life-partner, or parent. The foundation's goal is to financially assist these families as they deal with the loss of their loved ones, and struggle to move forward (parents with children under age 18 in the first year after losing a spouse).

COPYRIGHT 2011 Heidi Coleman & MitoAction.org. Permission required to reproduce.