

Summary – Coping with Mitochondrial Disease

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Stress related to Ambiguity

Mitochondrial disease poses many, many challenges because there are multiple sources of ambiguity - from diagnosis and treatment to prognosis. In addition, the general lack of knowledge and awareness about mitochondrial disease makes access to support even more difficult. In order to get a definitive diagnosis of mitochondrial disease, a patient may have to go through multiple doctors' appointments over a series of months (if not years). Even after all this, there may still only be a probable diagnosis. The uncertainty and ambiguity about the diagnosis may be even greater in parts of the country where little is known about mitochondrial disease. In addition, there may be un-definitive genetic changes identified which add to the uncertainty of the prognosis and future for the patient and the family. Treatments and treatment options also become problematic as different doctors offer different approaches depending on their experience (or lack of experience) with mitochondrial disease. For example, a physician experienced with mitochondrial disease may want the patient hydrated with an IV at the earliest signs of an infection while the ER doctor may disagree with this plan. Often Mito patients see multiple physicians for the various symptoms they have, it is not uncommon for those specialists to disagree on a mode of treatment! All of this only adds to the uncertainty and stress that the patient and family with mitochondrial disease must endure.

In addition, stress is a natural consequence when patients feel that they must "prove themselves" or when parents feel they have to "justify" their concerns because, to the less experienced provider, teacher, etc., the adult patient or child appears "fine." One parent quips, "Explaining that my perfectly healthy looking child needs to pace his activities so he won't become fatigued is completely lost on those unaware of the disease and its symptoms...until the end of the day when my child can hardly walk or talk anymore." The pressure and burden of self-advocacy can lead to doubt and stress - all the while dealing with the multiple symptoms of the disease.

Uncertain Genetics

Because the genetics of mitochondrial disease transmission are complex, the exact mode of transmission is not always known for many patients. This uncertainty adds more stress to the already stressed family. Family members feel uncertain about who else in the family might have the disease. Further, because the symptoms of Mito are common to other disorders (like headache, fatigue, GI problems), parents and siblings may have fear about "the disease" every time they feel ill.

Genetic testing, including muscle biopsy for diagnosis, is very expensive and some insurance plans may not cover some of these tests. Families are again often left uncertain about the cause of the disease and the probability of other members also having it. The landscape of mitochondrial medicine is rapidly changing, so that each year as knowledge about mitochondrial disease improves, the facts or interpretation

may also change. For example, some patients assumed their disease was inherited from their mother (mtDNA), then learned later that this was not the case. Though it is good that knowledge improves each year with more research, this does add to the patients' and families' uncertainty, and stress.

Prognosis

It is impossible to predict the course of mitochondrial disease. A person may lose skills or functions during the course of an illness or infection, and may or may not then gain them all back. Nonetheless, when the regression occurs and/or during particularly "low" energy periods, it is very difficult to cope. When a patient or child has certain specific symptoms, we want to know, "Does this mean that the disease has progressed?" Maggie Orr states, "It is impossible to answer, because as health care professionals, we truly do not know." Sometimes the "not knowing" is as difficult as "knowing."

Coping with these uncertainties

Carole Slipowitz assists patients and parents in our mitochondrial disease community through the Mito 411 (1-888-MITO 411) toll-free volunteer support line. She notes, "It is very hard to live in a state of chronic stress, and my best advice is that Mito patients and parents of affected kids need to learn to get through each day first." Priorities need to be focused on self-care, as this is something that we can control. Remember and remind yourself what it is you love in life and who the people are that make you feel better...then do those things and see those people.

Specific sources of help (see complete list at the end of this summary)

- Relaxation or Meditation: There are all kinds of sites on the Web that have soothing audio sounds and visuals that last only 6 minutes (try a YouTube search for relaxation therapy).
- Coping with Chronic Illness: Though not specific to Mito, there are many sites designed to offer support and suggestions for coping with chronic illness.
- MitoAction site: The forum is a way to connect with other people for support, and the articles in the blog and in the "Tips for Living with Mito" section offer many helpful hints and practical advice for patients as well as parents of children with the disease.
- Humor: FIND humor and make an effort to have humor in your life - through cartoons, jokes, talking, movies, comedy shows, books - we need to laugh!
- Environment: Surround yourself with whatever you think is beautiful. This can be pictures, posters, even your screen saver. A peaceful environment that you create can help you to feel calmer and in control. Peaceful touches in the environment (music, colors, scents, pictures) are helpful for children also - especially those who are hospitalized frequently.
- Ask for the "H" word...Help: Think of those people in your life who have helped you before, people who you like to have around, and ask them for help. Minimize the time you spend with people who don't make you feel good. This is your right!
- Support Organizations: Use them! Use the Web to search various support organizations - examples include caringbridge.org, and the yahoo based Mito

email groups MitoAction offers free telephone support groups on Fridays each month - check the website calendar for details.

Grief

When facing a diagnosis of something like Mitochondrial Disease, it is important to acknowledge feelings of grief. There is the grief of the parents over the life they had dreamed or imagined for their child, and there is grief for the adult of the loss of the life they thought they were going to have. Do not underestimate the impact of this grief, and the time that it takes for a person or family to heal. It helps to understand that there are stages of grief that people move through. One author describes a series of overlapping stages that one might go through (*Coping with Chronic Illness* (www.alpineguild.com)). First there is the crisis stage which usually lasts only a short time and is followed by isolation - the person is exhausted by the crisis and now just feels totally alone and wants to be alone. Inevitably the person becomes angry at the diagnosis, which can evolve into fear, anxiety and depression. Much of this anger and depression is based on the losses and expected losses people believe they have or will suffer. Most people can have a certain expectation of what their life might be like - it is extremely difficult to not know. Then there is the stage of reconstruction; life is not like it was before but you can reconstruct your sense of self, or your sense of "normal" for your family. Despite this, one might still encounter bouts of depression which need to be countered with more renewal. Support is very, very important.

These are all strong emotions and individuals need to find safe ways to express these feelings. There may be times and circumstances where to express feelings would be inappropriate (at the yearly specialist's visit, at a friend's birthday party) even though these are the situations where the feelings of depression, anger, fear, frustration and sadness may be the most evident. Finding a safe place and manner to express these feelings is essential.

A consequence of the unpredictable nature of mitochondrial disease is that there is no "game plan". The medical or education team can't describe what will happen first, then second, etc, because they just don't know. In most cases, the family or the patient with mitochondrial disease must set up their own personal game plan, and be ready to change the plan without notice. This entire process can be very exhausting.

Lack of Awareness

The lack of awareness by the general public as well as by the medical community about mitochondrial disease can be a source of additional stress to patients and their families. A diagnosis of Mito is not like a cancer diagnosis in which the patient's family and friends are likely to already understand the disease and can "rally around" the person with the diagnosis. MitoAction has many resources to raise awareness, including an awareness kit (email to request one) and the videos and personal stories, especially those under the *Awareness* section and *Living With Mito* section. Unfortunately, even family members can deny that there is an illness present if they cannot see it. It

becomes very important that the patient or person caring for the child with Mito find others who understand the disease and get support from them.

A diagnosis of mitochondrial disease might mean that the patient or family must redefine his or her life. There is a natural selection process that takes place during the course of a diagnosis and disease like mitochondrial disease where each of us must reconsider and re-evaluate who our friends are, and what we need from our friends and family. It is a normal and healthy choice to, in some cases, distance oneself from those friends and family who do not understand or do not offer support and validation for the challenges that come with a life with mitochondrial disease.

Parents and patients facing mitochondrial disease must find their inner strength. Often, parents feel that they know their child best and feel that they must be "the voice" for their child. Adult patients best know his/her own body and what they are going through. It is important that healthcare providers, family, teachers, friends, etc. do not doubt the symptoms. When dealing with intense feelings toward people who do not understand or offer support despite the circumstances, consider writing down angry and emotional thoughts to these people but then just throw the paper away. Parents and patients with mitochondrial disease can get support from others in the Mito community - and together we can help one another to focus on the positive.

Rethinking expectations

Along with the diagnosis of mitochondrial disease comes the need to be willing to adjust one's expectations - for yourself, your child, your family, your loved one, and even of those around you. Just because the child or the patient is dealing with mitochondrial disease doesn't mean that all of our dreams must be eliminated, but the path to reaching our dreams may be different, and will probably take longer. Many families and patients find that by giving themselves plenty of time to rest, and by choosing and scheduling activities very carefully, quality of life is not so difficult to obtain. It is often very hard to ask for help, but learn to go to those people who have helped in the past and made you feel good. Different people and resources offer different things - seek some emotional support and others for concrete action or assistance. MitoAction hosts teleconferences every Friday for different members of the Mito community, which is an excellent and easy way to find support. Many adult patients emphasize that getting involved with the Mito community can be a great help., as it is difficult to cope alone. The disease is not a smooth narrative but rather a circuitous one.

Educating others

Sometimes the burden of explaining to others why your child can't do something or explaining to another adult what Mito means may be just too time consuming or energy draining. Often others respond by saying, "but the children are so beautiful" or "you don't look sick." This burden of advocacy can take its toll on your energy as well. So, when needed explain, but try to be realistic about the reaction and response of others. As parents, it is good advice to let your children have their dreams - every day you can choose to "live in life mode not survival mode". Take each day as it comes, cope with the bad days and move on to enjoy the good ones. Educating others about the disease

does not have to fall on your shoulders alone. Slowly information about Mito is spreading from coast to coast and more and more is learned every day. There is hope for all Mito patients and their families. The conscious choice to focus each day on what you or your child can do rather than on what we cannot do allows us to move forward and make positive choices and set realistic goals. Reach out for help - don't try to go it alone, and know that there are others in the journey with you.

Summary prepared by Cristy Balcells RN MSN and Joanne Turco, RN, MS

Some useful resources, suggested by Carole:

Websites:

MedlinePlus section on coping with chronic illness: www.nlm.nih.gov/medlineplus/copingwithchronicillness.html

www.healingwell.com

www.bravekids.org

caringbridge.org

American Chronic Pain Association: www.theacpa.org

www.fathersnetwork.org This website has a large list of resources listed under "links to related sites."

www.sn1.depaul.edu/StudentResources/Chronic_Illness/index.asp For adult students who have chronic illnesses.

www.mbmi.org/basics/whatis_response_elicitation.asp

speakingoffaith.publicradio.org

This is the website of an award-winning public radio program. You can read transcripts and listen to podcasts of various shows, including:

Listening Generously: The Medicine of Rachel Naomi Remen

Heart and Soul: The Integrative Medicine of Dr. Mehmet Oz

The Spirituality of Parenting

Robert Coles and the Inner Lives of Children

Stress and the Balance Within

Opening to Our Lives

Meditation and relaxation on the internet:

from the American Chronic Pain Association: <http://www.theacpa.org/people/videos.asp>

www.beliefnet.com/Health/1999/12/A-Moment-Of-Calm.aspx

<http://www.beliefnet.com/Health/Emotional-Health/Depression/The-End-Of-Suffering.aspx#>

www.dharma.org/ims/mr_audio.php Includes longer guided meditations

There are many relaxation, meditation, and guided visualizations available on: www.youtube.com

You can put phrases like this into the search box at the top of the page to find them. Some I particularly like are categorized under "relaxation therapy":

www.youtube.com/watch?v=etky4i_H7hE

www.youtube.com/watch?v=Tha3qYEc1cc

www.youtube.com/watch?v=etJrEX47sDU

Blogs:

www.sickandhappy.com by Julie Desch. See especially her post "Ants and Elephants"

invisibleillnessweek.com See especially "54 ways you say you respond to "you look so good!"

achronicdose.blogspot.com This blog is by Laurie Edwards, author of the book Life Disrupted.

workingwithchronicillness.com

www.blogcatalog.com/blog/the-invisible-chronic-illness-experience

Articles:

www.mitoaction.org A number of articles, including

www.mitoaction.org/blog/coping-with-childs-diagnosis

www.mitoaction.org/blog/parent-patient

www.mitoaction.org/taxonomy/term/9 (Dr. Gwenn's Mito Minutes)

[www.alpineguild.com/COPING WITH CHRONIC ILLNESS.html](http://www.alpineguild.com/COPING_WITH_CHRONIC_ILLNESS.html)

www.shareguide.com/Remen.html

<http://www.nationaljewish.org/pdf/Understanding-ChildrenChronicIllness.pdf>

occupational-therapy.advanceweb.com/Article/Reaching-for-Possibilities.aspx

www.fathersnetwork.org/647.html (Coping with Chronic Illness)

www.fathersnetwork.org/762.html (Enhancing Family Resilience)

thyroid.about.com/od/alternativeholisticinfo/a/chronicdisease.htm

restministries.com/?cat=5

Books:

I have read and can personally recommend the first three books on this list. The rest of the books have received good reviews from others. Many are available through local libraries. It's worth remembering that many libraries can now grant you a computer account, and you can request a book that way. If your local library doesn't have it, it may be available through Interlibrary Loan. When you request a book in advance, it will usually be held for you at the front desk of the local library, which will save you the energy of having to search through the shelves.

- A Delicate Balance: Living Successfully with Chronic Illness by Susan Milstrey Wells
- More than a Mom: Living a Full and Balanced Life When Your Child has Special Needs by Fawcett and Baskin
- Maureen Garth's books of meditations for children are great at bedtime
- The Chronic Illness Workbook: Strategies And Solutions for Taking Back Your Life by Patricia A. Fennell
- Chronically Happy: Joyful Living In Spite Of Chronic Illness by Lori Hartwell
- After the Diagnosis : From Crisis to Personal Renewal for Patients With Chronic Illness by Joann Lemaistre
- Just Fine: Unmasking Concealed Chronic Illness And Pain by Carol Sveilich
- You Don't Look Sick: Living Well with Invisible Chronic Illness by Joy H. Selak
- Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness, Second Edition by Paul J. Donoghue and Mary E. Siegel
- Life Disrupted: Getting Real About Chronic Illness in Your Twenties and Thirties by Laurie Edwards
- Mainstay: For the Well Spouse of the Chronically Ill by Maggie Strong
- Chronic Illness and the Twelve Steps: A Practical Approach to Spiritual Resilience by Martha Cleveland
- Finding the Joy in Today: Practical Readings for Living with Chronic Illness by Pitzele
- We Are Not Alone: Learning to Live with Chronic Illness by Pitzele
- The Art of Getting Well: Maximizing Health and Well-being When You Have a Chronic Illness by David Spero
- Be Sick Well: A Healthy Approach to Chronic Illness by Jeff Kane
- Invisible Illnesses and Disabilities by Sharon Smith-Merritt (memoir)
- Books written by Rachel Naomi Remen

- Building a Joyful Life With Your Child Who Has Special Needs by Nancy J. Whiteman
- Breakthrough Parenting for Children with Special Needs: Raising the Bar of Expectations by Judy Winter Wrightslaw: From Emotions to Advocacy: The
- Special Education Survival Guide by Peter W. D. Wright and Pamela Darr Wright
- Changed by a Child by Barbara Gill
- Feeling Good: The New Mood Therapy by David D. Burns