

'Coping With Guilt'

Emotions run rampant when hearing that our child has MCAD (or any of the FODs). We may have experienced feelings such as disbelief, denial, anger, fear, confusion, emptiness, and anxiety. **One emotion that we often experience when told that our child has a hereditary disorder is guilt. It can be especially intense if a child (children) dies because MCAD was not detected early enough or if it wasn't detected at all.** Unfortunately, many of us have learned about MCAD only after reading lots of articles, talking with experts, and having autopsy tissues reexamined.

Guilt does not 'discriminate' ~ all of us with MCAD children, living or deceased, most likely have experienced this common and pervasive emotion to varying degrees. There are various causes for guilt, but the **focus of this piece will be on guilt due to the feeling that we are responsible for our child (children) acquiring MCAD, that we have failed him or her, and that he or she may have died because we didn't fulfill our parental duty, albeit unrealistic, of protecting our child from harm at all times.**

Even though intellectually we know we cannot control everything, we still feel we should have prevented our child (children) from acquiring MCAD and/or prevented our child's death from occurring. **Guilt feelings arise because of the discrepancy between what we think we SHOULD be able to do and control and what we ACTUALLY can control and achieve as parents.**

In order to deal with these guilt feelings, some may have turned to self-destructive behaviors such as excessive drinking and/or the use of drugs in order to drown or avoid feelings. **Processing and coping with guilt takes a great deal of energy** and using negative strategies may actually delay guilt reactions and 'resolution' of those feelings, as well as delay/complicate the entire grief process.

More positive strategies include confronting and admitting to yourself your feelings of guilt, sharing with your family and friends your feelings of responsibility for your child acquiring a genetic deficiency, learning more about guilt reactions and discovering how normal they are, and trying to forgive yourself for not being perfect. **Unfortunately, all those should, ought, and must statements we (and sometimes society) tell ourselves quickly trigger our feelings of guilt.**

Confronting and admitting that your guilt feelings exist is helpful in acknowledging the reality of the situation. Of course, this does not happen overnight and it takes ALOT of emotional and psychological work. In order to cope with the negative feelings, we can try to think of them in a more positive light by the using reality testing. For example, as soon as we heard the MCAD diagnosis, we may have had thoughts such as "Maybe we shouldn't have had children in the first place,

look what happened." But once we carefully examine our reasons for having children in the first place (i.e. as an extension of our love, etc.), we can focus on our decision in a more positive manner. Hindsight is always 20/20 ~ we've probably all heard that more than we can count, but when the decision to have children is made, realistically we are going on the information we have at the time and we most likely felt it was the right thing to do.

For **those of us who have continued our families after a child's (children) death** and now armed with the knowledge of MCAD, **guilt feelings** about passing the gene on may still be present, but may be somewhat **temporarily overshadowed by the feelings of fear and anxiety of what lies ahead if another child is diagnosed with MCAD**. These feelings must also be confronted and dealt with. ('Coping with stress' is discussed in a separate article on this site).

The main point, though, is that **guilt is very common and very pervasive**. It can ebb and flow over time and in order to cope with these feelings, we first **must confront and admit that these feelings exist**. In many cases, moving through guilt can evoke other intense feelings that must be dealt with in order to have some sense of 'healing.' Hopefully there is someone that you feel comfortable with sharing those intense emotions, but if there isn't then maybe seeking professional help would benefit you, **so guilt and other unresolved emotions don't keep you 'locked' or 'stuck' in your process**.

Another way of coping with guilt is by **changing our irrational beliefs** of "I must be a perfect parent," "I should have known about MCAD" and "If I was doing my job as a parent, this shouldn't have happened." Again, once we **examine how unrealistic these statements are, we can put them in perspective**.

We, **as parents, are so hard on ourselves and we may have to learn how to forgive ourselves** (which is much easier said than done) for not being 'perfect and all-knowing.' Forgiving ourselves is often very difficult to do, especially when just thinking about it. **Writing your thoughts down in a journal** may be helpful in that you have something tangible to read and you can better see some changes when you look back at earlier entries. Those of us who have had a child die may have used this suggestion in order **to release our feelings, lower their intensity over time, and to understand our beliefs and feelings in a more realistic manner**.

Although it will not bring our other children back, we are probably thankful that we now at least know about MCAD and we can try and be positive about our present and future MCAD children. **Their lives are not doomed for death**. Yes, there is stress involved with the everyday medications, making sure they eat, and when they get sick, but the positive prognosis for a 'normal' lifespan is very encouraging. **Focusing on what we CAN do in the here and now may lessen the intensity of feeling guilty** about passing the gene on to our child.

Lastly, **reaching out to other MCAD families can be a way of discovering that we are not alone** in our feelings of guilt as well as a myriad of other emotions. Of course, doctors that specialize in inherited metabolic disorders are familiar with the medical aspects of MCAD, and hopefully your family physicians are becoming better educated about how to deal with your child's circumstances, but **we, as parents, are the ones who are dealing with the day-to-day practical and emotional situations.** It may be comforting and encouraging if we can communicate with one another to pass along helpful suggestions on how to deal with certain issues. Expression and communication of those feelings are important aspects of dealing with life issues. **We hope that this newsletter and website will spark not only communication within your own families, but with families across the country and the world!**

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Note: This article appeared in the very first issue of the MCAD Communication Network, Volume 1 Issue 1, February 1991. Since that time, the Support Group and Newsletter have expanded from MCAD to include all of the Fatty Oxidation Disorders.