

'Coping With Stress'

"Your child has MCAD." After your initial shock wore off, **these words may have driven fear and anxiety into your entire being.** What does having MCAD (or any FOD) mean to your child, yourself, and your families? How CAN we and ARE we capable of coping with the stresses of this rare medical disorder? How does the stress of coping with MCAD and/or a child's death manifest itself in your life? What can we do to deal with our anxieties and fears?

I'm sure all of us would admit to experiencing increased stress after an MCAD/FOD diagnosis and/or death. Facing the unfamiliar and unknown can be very frightening. We may endlessly ask ourselves "Will we ever be able to survive? Is it our fault that our child has MCAD? How do we handle things when he/she gets the flu or chickenpox? Is he/she getting enough food and carnitine? What if our future children have MCAD, too? What if... what if ... what if... ?"

These questions and many others are very normal for us to ask and are not unique to those of us coping with an MCAD child. I'm sure if we had a teleconference with other parents dealing with medical disorders, we'd hear very similar fears.

These fears may possibly be experienced as feelings of panic or as an overall anxiety. We come to realize that **being in 'total control' is no longer our reality.** At first, our new reality is so unreal and very stressful. Our powerlessness in being able to protect our child(ren) from MCAD and/or death may lead to panicking in specific situations or feeling uptight all the time about everything and everyone. We may be overwhelmed by no longer having a 'normal' life. Our thought of "It only happens to other families" is a lie. **We now know the hard truth!**

All of us undoubtedly have experienced varying amounts of stress since our child's(ren's) diagnosis and/or death(s). Yet, this similar stressor may have caused differing reactions in our bodies and minds. **How we cope with stress depends on a variety of factors** such as your perception or view of the situation, past coping strategies, other losses and stressors, your present physical and mental state, and the support (or lack of) from family, friends, medical community, religious community, and support groups.

Those of us that have not only dealt with an MCAD diagnosis, but with the death of a child(ren), may have experienced (and still experiencing) unique stresses. Not that other MCAD Families don't experience these stresses, they are just different in 'texture' in relation to bereaved families. Many times, when a death occurs, the 'end of the world' has come ~ our past coping strategies may fail us, we've lost our family the way it was 'supposed to be,' over-protectiveness of surviving children and marriage problems may occur, our bodies and minds may go haywire with illnesses and/or over-exaggerating other situations, and we lose

much needed support when some people make us feel like social outcasts because they don't know how to 'fix' us! Of course, this may not be the total picture for every parent or family, but I think it is safe to say that stress, as well as our vulnerability, is at its peak after a death.

Viewing any situation negatively (i.e. my future children are doomed) will definitely affect how you cope, as compared to viewing it positively (i.e. thank goodness we found out in time). Instead of using healthy coping strategies (reading, exercise, expressing emotions), you may have chosen less positive ways (alcohol, total withdrawal, over-protectiveness) to deal with the immediate concerns, as well as other existing pressures. You also may have let yourself get rundown. In other words, **you may be so busy taking care of your MCAD child's needs that you forget to take care of yourself, physically, mentally, and spiritually.** In addition, your families and friends may be so discouraged by not being able to 'help' you, that you lose a much-needed source of support.

So, **what CAN we do about all of our stress?** Realistically, we know it's not going to totally go away, but there are ways of positively dealing with anxiety. Listed below are a few suggestions for healthy coping. These can be applied to all kinds of stress besides the ones associated with MCAD or any other FOD.

1. If you have a serious concern about your physical or mental health, consult your physician or other qualified professionals. Medical or psychological concerns should be ruled out and in some cases, medication and/or counseling may be temporarily necessary.
2. Journal and/or talk about your thoughts, feelings, and behaviors before/during/after stressful situations.
3. Read about MCAD if you have access to medical journals or the Internet. Some of us may need a medical person to interpret the oftentimes-difficult language, however! Self-help books on stress may also be helpful. Knowledge is power.
4. Exercise to release frustrations, as well as to keep you fit. Diet changes (i.e. decrease caffeine) may help. Hobbies are a good stress reliever, as well.
5. Be proactive and network with other MCAD families and/or other support groups.
6. Thought stopping and reframing ~ Work at telling yourself to stop thinking about a particular thought and replace it with something different or try to turn your negative thoughts around to a more positive perspective. **Note: Thought stopping is not recommended for individuals working through grief. Thoughts and emotions MUST be processed in order for healthy grieving to occur.**
7. Find a physician for your child that you feel comfortable with and will take your concerns seriously.
8. Take time for yourself. If possible, get away from things for a while ~ even if it's just for a few hours.

For our sake and our families' sake, we should all make an honest assessment of our current coping strategies and strive toward healthier ways of dealing with stress.

We must take care of ourselves! Our children and families will be most thankful that we did!

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Note: This article appeared as a follow-up article to 'Coping With Guilt' and appeared in the MCAD Communication Network, Volume 2 Issue 1, June 1992. Since that time, the Support Group and Newsletter have expanded from MCAD to include all of the Fatty Oxidation Disorders.