

MCAD Communication Network
'All In This Together'

June 1992

Volume 2 Issue 1

From The Editor

Happy belated Mother's Day wishes to all our MCAD moms! Dan and I hope your day was special. Fathers, we're not forgetting you - Happy Father's Day on June 21st!

In this issue, you'll notice that we have added some new features. We hope you like them. Please feel free to offer suggestions on how to make our newsletter better. Suggestions (or actual written material) on articles, your stories, questions, layout, etc., are badly needed and would be GREATLY appreciated. Our next issue will be in January.

We all know how stressful life can be at times. So in this issue we discuss how dealing with MCAD can add extra stress on families. Assessing our individual coping strategies is explored and suggestions are made for healthier ways of dealing with anxiety.

I would like to thank Teresa Miller for sharing her family's MCAD story. Dan and I hope that more of you will share your stories with us so that we can begin to 'know' each other a little better.

In this issue questions are answered, but due to circumstances, the pharmaceutical and medical updates will be printed in the next issue. We have also added a LOVE MESSAGES section for families that have experienced an MCAD child's death. Special days and holidays can be especially difficult to deal with. Please remember them in your thoughts or prayers.

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Coping with Stress

"Your child has MCAD." After your initial shock wore off, these words may have driven fear and anxiety into your whole being. What does having MCAD 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 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 ~ even though it never really was anyway! 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 thoughts 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) 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, 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. 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 and over-protectiveness of surviving children and marriage problems may occur, our bodies and minds go haywire with more illnesses and/or over-exaggerating situations, and we lose much needed support when some people make us feel like social outcasts. 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.

Families dealing with an MCAD diagnosis who have not had a child(ren) die, may also experience these types of stresses to some degree. Viewing the situation negatively (my child is doomed) will definitely affect how you cope, as compared to viewing it positively (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 may have also let yourselves 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 yourselves, physically, emotionally, 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 some suggestions for healthy coping. These can be applied to all kinds of stresses besides the ones associated with MCAD.

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, short-term medication may be 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. Some of us may need a medical person to interpret the sometimes 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 (decrease caffeine) may help. Hobbies are a good stress reliever, as well.
5. Network with other MCAD families and/or other support groups.
6. Thought stopping and reframing: Tell 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 and integration 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. Get away from things for a while ~ even if it's for a 15 minute walk around the block.

In conclusion, 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 thankful that we did!

Deb Lee Gould, Director

She's a Miracle

Our daughter, Jessica, became ill with a stomach virus in May 1990. At the time, she was two-years-old. Our pediatrician was not alarmed and he treated this case as he had hundreds of other stomach viruses ~ it would have to take its course.

After two days of vomiting and eating next to nothing, Jessica became quite lethargic. In the early morning hours on May 10, 1990, we heard groans coming from her room. Within seconds, we found her having a seizure.

We could not wake her and she was as limp as a rag doll. We rushed her to the hospital and upon arrival, it was discovered that her blood sugar level had dropped to 16. The Emergency Room doctors didn't know the cause, but they immediately administered a glucose IV. With Jessica still in a coma, doctors ran test after test, none of which pointed to a definite cause.

They let us talk and sing to her and the excruciating seconds turned into hours. No one knew what was wrong and we felt so helpless. Before we were allowed to go in with her, we called our family and a few friends and a prayer chain immediately began. God was listening and we began to feel His presence. After about five hours, Jessica had stabilized enough to be moved to Vanderbilt Children's Hospital. It was then that she opened her eyes for a brief second and we knew she had to be okay. Twenty-four hours after this ordeal began, Jessica awoke from her coma and seemed to be perfectly normal! It was Dr. Jennifer Najjar, a pediatric endocrinologist at Vanderbilt, who was able to fit the pieces together and diagnose Jessica with MCAD.

Jessica will be four on March 25 and she is healthy, happy, and very active. She has been hospitalized twice since her first episode with MCAD. She has asked a few questions about her condition, but thanks to the newsletter, we have been able to tell her that her body is just a little different on the inside, even though she looks like others on the outside.

We came so close to losing Jessica that May and we know that it is truly a miracle that she is here with us today. We will continue learning as much as we can about MCAD and teaching Jessica to take care of her body. We know it won't be easy for her to be hospitalized every time she becomes ill and as she grows older we may face many more problems, but we know it could have been so much worse ...Thank you, God.

Teresa Miller
Murfreesboro, TN

Questions and Answers

[Please Note: This question and answer column is designed to answer questions, both medical and practical, on MCAD and its treatment. Answers to questions are solicited from those who have had firsthand experience dealing with MCAD. These include physicians, parents of MCAD children and children themselves. It is our hope to provide general guidelines in responding to questions posed as opposed to specific foolproof solutions. Additionally, it is especially important to note that our Medical Advisor, Dr. Charles Roe, (at printing of this newsletter in 1992, he was at Duke University Medical School and now, in 2000, at Baylor in Dallas) has read and approved responses to all medical questions. However, because of the individual nature of each case, it is always important to discuss these guidelines with your physician before making any changes.]

Question: When we were on vacation and out of our usual routine, I forgot to give my child 1 dose of carnitine. Should I give her a double dose for the next scheduled dose?

Answer: If your child is well, a double dose won't be necessary. She can wait until the next scheduled dose. If she is on a regular schedule of 3-4 carnitine doses per day, then she already has a good supply of carnitine in her tissue. Missing one dose will not have a negative effect on the well-saturated tissue. If your child has a fever (without vomiting), you could also wait for her next dose. During a fever, though, it is recommended to double each dose for 48-72 hours and to offer high calorie drinks if her food is not too appealing. However, if she is vomiting and/or has severe diarrhea, it is important to seek immediate medical care. Illnesses may place your child in a fasting state and her metabolic rate speeds up. These are situations that the glucose IV and possibly the carnitine IV may need to be used.

Question: I'm always looking for snacks. Can you give me some ideas for good snacks?
(Asked by Mark Barilla, 7yrs-old)

Answer: When parents are shopping for treats and snacks, it's a good idea to get the children involved, too. Show them where the ingredients are and have the older children read the fat content. Finding low-fat snacks is important, but you do not have to be rigid in what you let them choose. Allow for choices and then have them available in the house. Higher fat than usual treats are okay every now and then, too. The following are some ideas for snacks or treats: yogurt, pretzels, bagels, raw vegetables, fruit, mozzarella cheese sticks, jello squares, cheese pizza, jelly beans, frozen fruit drinks, sherbet, ice milk, angel food cake, crackers made with grains, graham crackers, fig cookies, and vanilla wafers. Enjoy, but remember moderation!

Question: What is in the carnitine IV solution that is different than the liquid we use for daily doses?

Answer: As of this printing (1992), L-carnitine (all forms) still has not been FDA approved. It continues to be considered an experimental drug. Dr. Roe is not familiar with what is in the commercially made carnitine IV, but he was able to offer some information about the solution made at Duke University Medical Center. He stated that their IV is pure L-carnitine and has no added preservatives. It is more concentrated than the oral liquid carnitine. For each oral dose, only 15% is absorbed by the body, less if the child has diarrhea. In comparison, 100% of the L-carnitine IV is absorbed in the body when it is directly injected into the vein.

Love Messages

Please remember the following families in your thoughts and prayers throughout the year~

Jeanne and Mark

Michael ~ Birth Feb 2, 1990 Death Nov 25, 1990

Deb and Dan

Kristen ~ Birth Oct 6, 1983 Death July 21, 1985

Debbie and Dave
Lauren ~ Birth May 4, 1988 Death Dec 15, 1989

Christine and Mark
Erin ~ Birth Aug 26, 1988 Death Jan 21, 1989

Brian and Cherryl
Kylie Ann ~ Birth Feb 7, 1990 Death Feb 11, 1990

Rick and Stephanie
Trinia ~ Birth July, 1977 Death Jan 14, 1978

Richard and Amy
Andrew ~ Birth May, 1978 Death Nov 18, 1979
Scott ~ Birth May, 1983 Death April 25, 1985

(Please Note: I have deleted last names for privacy reasons. Even though we publish our Love Messages in EACH printed issue, this section will only be printed again in the most current newsletter's online issue.)

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[Please Note: Our Group began in 1991 as the MCAD Family Support Group ~ in 1996 we expanded to include all of the Fatty Oxidation Disorders (FODs). Please be sure to read the most current newsletters to get the most updated information on FOD diagnosis, treatment recommendations, research, and names of FOD researchers/Labs.]