



When Your Child Needs Surgery...

Some helpful tips and advice from
families who have been through it
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When MHE Makes You Nervous MHE - and - MHE, Stress and Parents

by Diana Fletcher, Stress Reducing Strategy Speaker, Author and Life
Coach

(and mother of a child with MHE) -
Valuable advice for both children and parents.

**THE MHE COALITION
MHE and Me**

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Preparing for Surgery

- ◆ Find out everything you can about the surgery, hospital procedures before hand (Will you be allowed to accompany your child into the operating room and stay with him or her while anesthesia is being administered? How will anesthesia be delivered? Will you be allowed into the recovery room, and when? Will a parent be allowed to sleep in the child's room, visiting hours, etc.). Don't assume that every hospital allows the same level of parental participation. Knowing as many details as possible will help make you less anxious, and you'll know that you'll be able to keep promises that you make! A calm parent makes for a calmer child. If you are having difficulty dealing with your own anxiety, speak to your doctor about ways to handle it.
- ◆ One thing that may help your child prepare for surgery is a hospital tour. The child can get a first hand look at the table, the lights, and the equipment, and receive explanations of the procedures so that little is left to the imagination and fears may be allayed. The pre-hospital tour can be helpful for the whole family.
- ◆ If surgery is being done at a large medical campus, look at a map and know where everything is before you go! It's easy to get lost, especially when you're anxious and feeling overwhelmed. Maps, detailed directions and other information may be available on the facility's website.
- ◆ If you are unable to make it to the hospital for a tour, there are online hospital tours available. One such tour can be found at the Band-Aides & Blackboards Web Site: <http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/hospital.html>. The facility you are going to may offer its own tour online. Check the website.
- ◆ There are books available to help kids of all ages deal with their anxieties about undergoing surgery. An MHE and Me favorite is: "Franklin Goes to the Hospital" by Paulette Bourgeois and Brenda Clark
- ◆ To help make pre-ops go a little easier: Start drinking lots of water 2 or 3 days before going to the hospital to make veins nice and "plump", so that pre-op blood work and the IV will go easier.
- ◆ If your child will need crutches, a walker, or a wheelchair after surgery, try to arrange for pre-surgical training. It is a big help if a child can learn to get around before he or she is experiencing post-operative pain.
- ◆ Have your doctor give you prescriptions for pain medication prior to the surgery, so that you can have it filled and waiting for you at home when you arrive back from the hospital. Most children only need prescription pain medication for a few days. Speak to your doctor about "layering" Tylenol with Motrin after surgery, which means giving Motrin or Tylenol, then a specified number of hours later giving the other. As always, **be sure to check with your child's physician about any medications**. You may also want to have Benadryl on hand, for the "itchies" that often seem to occur after surgery.
- ◆ Will your child be in a cast or an immobilizer after surgery? Before surgery is a good time to try ways to get in and out of the car, up and down stairs, etc. Wrap your child's leg or arm in a big towel, then playact how you will be able to many families wish they had thought of before their child's surgery. The logistics of getting in and out of the car, then having to carry a child into the house, then upstairs, can be things that haven't occurred to you and can be very, very difficult. When children are involved in the planning, they can be very creative at figuring out ways to move around, and you'll be more accomplished at moving them without causing pain and anxiety.

- ◆ If your child is experiencing severe anxiety in the days leading up to surgery, he or she may benefit from deep breathing exercises, or talking through fears, etc. If none of that works and your child is in real distress, you may want to talk to your child's doctor about a prescription for valium or other medication to help your child relax.
- ◆ If you have a lot of people who will want to be updated on your child's surgery and progress, you may want to sign up at Caringbridge.org for a free webpage that will enable you to post pictures and a blog of what's happening. Only people with the page information that you provide them with can view the site, and you can have a family member or friend provide the updates if you're not available. It will save you a lot of time, phone calls and energy that you'll need for your child, and your child can help design the page before going into the hospital, and even post his or her own updates before and after surgery!

A pre-surgery shopping list might include items like:

- ◆ Flushable wet wipes (sometimes a bedpan is necessary for a day or so...), disposable, rinse-free cloths (like Comfort Bath), which you can heat in the microwave (they now also make the Comfort Shampoo Cap for a water-free shampoo). Liquid shower gel may be better than regular soap (which is harder to rinse off) for a sponge bath.
- ◆ Ginger ale or coke, Popsicles, *Jello*, crackers, etc., in case your child is queasy, something that can last for several days after surgery. Loss of appetite is common, and can last for awhile. Meal replacement drinks can be helpful, if your child will take them. Many are made especially for children now.
- ◆ Ice packs are often recommended for after surgery. There are many types available in drug stores, including gel packs that you just keep in your freezer. Put one in before you go to the hospital so it's ready when you get home. (You can also use a bag of frozen peas, which conforms to the area, then just refreeze after use. Just be sure to mark the bag. Since it will be in and out of the freezer, you won't want to cook them).
- ◆ After ice is no longer necessary, your child may prefer heat packs. Again, there are many types available in your drug store, including microwavable packs. (Another handy item for when you're ready to use heat: socks filled with raw rice (not instant) and tied at the top are microwavable and make great heat packs. Use different size socks for different areas! (Soccer socks can make great heat wraps for around the neck and shoulders! Heat for 1 minute, then a little longer if necessary. These can be good for parents with sore backs and shoulders from lifting the patient!).
- ◆ You may want to purchase some gift items for the child having surgery, as well as for siblings, and have them wrapped and ready for times when your child(ren) need them. They don't have to be expensive: craft items, jig saw puzzles, a little gift bag filled with snacks and candy, a new DVD the family can watch together. Things that relieve boredom can also help relieve pain and discomfort by distracting you child for a little while. It's also important to remember that siblings need to know that they're still important, especially when so much of your attention is going to the "patient".

Packing for the Hospital

- ◆ Pack a digital (or disposable) camera and get pre and post-op snapshots, plus photos of all the wonderful hospital staff. Have duplicates made and send the hospital a set, too! You may want to put some of the photos on your Caringbridge.org page, too!
- ◆ Bring a favorite movie to the hospital, labeled with own name. (Note: Double check with the hospital to make sure a DVD will be available for your child. Not all hospitals have them.)
- ◆ Bring a favorite soft blanket or pillow for cuddling with.
- ◆ Even if your child is scheduled for same-day surgery, it doesn't hurt to throw into a bag, toothbrushes, toothpaste, a clean t-shirt, and other essential items, just in case it

turns into an overnigher.

- ◆ Bring along a few snacks. You may not be able to get away for meals. Also pack any medications you might need, for headache, backache, etc. The experience can be both emotionally and physically stressful.
- ◆ Think ahead to what your child will wear home from the hospital. If the arm will be in an immobilizer or cast, you'll need something wide. If the leg will be in an immobilizer or cast, you will need wide leg, stretchy shorts or sweats that will fit over it, and loose-fitting socks and slippers can be of help, too. You'll also need underwear that can fit over the bandages, etc., so make sure it's stretchy enough!

The Ride to the Hospital

- ◆ Some families will be leaving for a long car trip, others to the airport for a flight to get to the hospital. When leaving early in the morning, make sure your child has plenty of blankets and pillows in the backseat (you'll need them for the ride home, too)...

In the Hospital

- ◆ Make sure you have a pad and pen with you to write down any instructions the medical staff might give, and to write down questions you might have. Keep track of when pain and other medications are given and when your child will be due for the next dose. There are times when you will need to make sure your child gets his pain medication on schedule. You don't want to wait until your child is hurting. Write down the name of the day and night nurses, so you don't forget!

The Ride Home

- ◆ Everyone agrees – bring plenty of pillows for the car, for the ride home. You'll want to cushion the area operated on, and make the patient as comfortable as possible. Another helpful item is a small plastic garbage can and some plastic liners, just in case your child gets sick on the way home. Keep some towels and wet wipes in the car, too.
- ◆ Chele has plenty of experience here and, besides collecting all bed pillows in the house, advises that driving home, take it slow, avoid railroad tracks, and time your departure after your child has had pain medication and it has begun to take effect.
- ◆ *Even though it can be difficult, be sure to use the seatbelt!*

When you Get Home

- ◆ *If possible, have someone set up the bed for the patient so it's all ready for your arrival. We usually have Nicole sleep on the living room couch for a few days post-op. It's a good height for her, and there is an easier path for her to get to the bathroom with her walker. There is also room there for me and her younger sister to camp out with her. We have the couch covered in several soft quilts, plenty of pillows, and that same plastic garbage can nearby, as nausea can continue for several days post-op. I usually wind up sleeping near Nicole for several days post-op. Depending on the recuperation and type of surgery, parents have been known to "camp out" for much longer periods.*
- ◆ *According to Chele, the day you come home from the hospital, and the next day, are the worst, so be prepared. She also advises that it will probably be between 5 and 7 days before you get a full night's sleep, so nap when your child naps, sleep when your child sleeps, and have plenty of coffee on hand!*
- ◆ *The first few days post-op, make sure that pain medications are given on schedule.*

Once pain starts, it's harder to control.

- ◆ *Remember that this is a hard time for siblings, who are bound to feel frightened when they see their brother or sister in pain, and left out and forgotten when their needs have to take a backseat to a post-op patient*

NOTES:

Questions for the surgeon: _____

Shopping list - foods, drinks, gifts, ingredients for make-ahead meals, etc.:

Packing list - items to take to hospital for your child, and for you. Make sure to have lots of pillows, cozy blanket, and small, plastic garbage can with bags in case of nausea and vomiting post-surgery. Make sure change of clothes for your child post-op takes into consideration type of surgery and if clothing has to be put on over cast, immobilizer, fixator, etc. Even if surgery is scheduled as same day, take along a few necessities for yourself, in case your child has to stay overnight. Toothbrush & paste, extra t-shirt, any medications you need, a book, charger for your phone, etc.

When MHE Makes You Nervous

by Diana Fletcher

(Reprinted from the Bumpy Bone Club Magazine)

There are so many things that can make you feel anxious about having MHE and so many parts of it that can cause you to get nervous or just plain sad. When you feel those things, it's called Stress. Stress is what happens when you have reactions to something that scares you or freaks you out. Your heart may race. Your breathing gets fast and you may even get sweaty. You may cry or have trouble sleeping. This stuff may not happen to you at all, or it may only happen once in awhile, but it would be nice to know what to do when it does.

There are things you can do that can make you feel better. They won't take away the reality of having MHE, but these actions can make it fade into the background for a little while, and sometimes that's what you need to have happen.

Wouldn't it be nice to have times when you don't have to think about MHE at all? And when you get scared, wouldn't it be nice to have something to do so that you wouldn't feel so afraid or discouraged?

Here are some things you can do that may help you when you feel worried, sad, or when something hurts:

1. Take deep breaths. You want to do this slowly. Put your hand on your tummy and breathe in through your nose. You want your hand to move up and that is how you know you are breathing deeply enough. Then blow the air out through your mouth and feel your hand go down. This can really help when you are worried and sometimes it can even help when you feel pain. Three breaths may calm you down and make you feel better. Try it! You won't believe how good you can feel when you do your deep, slow breaths!
2. Talk about what you are feeling. You may think that complaining is bad but it is very important to let your feelings out. You may find that some people are better to talk to than others or that someone outside your family, who doesn't really understand what MHE is like, may not be good to talk to. But you need to talk about it and get your feelings out. It doesn't have to be the only thing you ever talk about, but don't ignore what you are really feeling!
3. If you have trouble talking about your feelings, or even if you do have someone to talk to when you feel scared, it is still good to write down your thoughts and feelings, or draw pictures about your feelings. Sometimes it is easier to express your feelings that way. You can get a notebook for this and if you want it to be a private book, you can ask your family to respect that. Sometimes you may want to share what you write or draw, but it needs to be your decision.
4. Let yourself cry sometimes. I know you may not want to be seen as a crybaby, but everyone needs to cry sometimes, even grown-ups. Again, it's good to let those feelings out.

5. LAUGH. Tell jokes, and ask your family to tell you jokes. Get funny movies and read funny books. When you laugh, you will always feel better! Sometimes, force your laugh and see what that feels like. It can be kind of funny.

6. Ask your parents to read you stories or read them yourself. A book can take you away to other places in your imagination, and there are so many wonderful stories out there. Sometimes it's good to escape a little in our minds, and then come safely back!

7. If you don't have trouble with your hands or fingers, you can do word searches or color. Word Search Books can be good to have handy when you are in waiting rooms of doctor offices. Guessing games can be fun during long waits, too. You and your companion can play twenty questions, or alphabet memory games. (I went to the store and bought an apple...I went to the store and bought an apple and banana...etc.)

8. Make sure you get to sleep at a reasonable time. If you let yourself get tired, everything will seem worse. When your body is tired and stressed, little things become big things and it is harder to calm yourself down. It is important to get your sleep even when you want to stay up and play on the computer and watch T.V.!

9. Make sure you tell your family and your doctors if you have pain. No one wants you to be in pain, and it is important to let them know when you feel it. There are actions they can take to help you with pain. Tell them. (And remember to breathe!).

10. One important thing to remember: Whatever you are going through at any time with MHE, that part of it will not last forever. Sometimes we think that because something is a certain way, it will always be that way. With MHE, there are many, many times when it won't bother you. Think about those times rather than the times when you are having symptoms or surgery. Grown-ups have a saying, "This too shall pass." That means that things in life are always changing. Think about all the wonderful people you have in your life. Think about all the fun times you have had and will have. It can be fun to make a list of all the stuff you love about your life. Ask your family to make this list with you if you have trouble. Put the list upon on the wall or a bulletin board to remind you that life can be very, very good! MHE is just a part of you—it is not all of you!



MHE, Stress, and Parents

by Diana Fletcher

Reprinted from The Bumpy Bone Club Magazine

Many of the techniques I suggest for your children can work for you, too. When you are under stress, your body goes into overdrive. You are on high alert and your body can only stay this way for so long. Constant stress will wear you out and wear you down.

It is important, as a parent of a child with MHE and possibly a person who has MHE yourself, that you take care of yourself. There is so much stress involved with this condition: doctor appointments, decisions, missed school, surgeries, follow-up care, and the list goes on.

It is easy to forget to take care of yourself, but this is actually the most important thing you can do. If you take care of yourself, you will be better able to take care of your child and/or your own condition.

The ideas I listed for your children can help you and your entire family. All of the ideas are important for us to re-duce the stress in our lives. And remember that siblings need some help too. They can also benefit from the techniques I suggest.

As I advised your children, you need to practice deep breathing. This is one of the best stress reducing techniques I can share with you. When you get stressed, your breathing becomes shallower and you will not get the oxygen to all the parts of your body that need it. Every cell needs oxygen and this includes your brain. In order to make the best decisions, and take care of everything you need to take care of, you want your brain to be at its sharpest.

You also need to make sure you are getting enough sleep. This is the next most important strategy you can use to reduce stress. Sleep is what often suffers when we are busy, and it is the one thing that shouldn't! Turn off the television, turn off the computer, and stop doing work. Go to sleep. Your body needs the rest. When you are rested, the whole world looks different. Everything seems manageable and you are better able to cope.

Proper nutrition, lots of water, and a multivitamin can make a huge difference in your health and the health of your family. These are stress reducers that we some-times forget about when we get busy.

And the last stress reducer I want to suggest is to show each other love. Love, laughter, and finding joy in being together can make a huge difference in the lives of all those affected by MHE.

Diana Fletcher (c) 2009

Diana Fletcher is a Stress Reducing Strategy Speaker, Author and Life Coach. She has three children, one with MHE. She and her family live in Murrysville, PA. Learn more about Diana at her website: <http://thoughtsbydiana.com/>

If your child is having surgery, contact Susan Wynn at mheandme@yahoo.com with your child's name, age, address and date and type of surgery. The MHE Coalition provides "We Care" packages to children undergoing surgery, and when possible, to siblings as well, so include names and ages of siblings, too. We also provide Bumpy Bone Club Membership Kits to children diagnosed with MHE, their siblings, or children of a parent with MHE who may need help in understanding the disorder. We offer these services at no cost, so donations are welcome.

The MHE Coalition is a 501(c)(3) organization.

Donations checks should be made payable to MHE Coalition and mailed to MHE Coalition, PO Box 651, Pine Island, NY 10969.

We also accept donations of small toys, new DVD's, books, gift cards for iTunes and Amazon.com for older kids/teens, etc. for our We Care packages. Please feel free to contact Susan to find out what is needed! We greatly appreciate all help.

For more information, please visit our websites at:

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