

Transplant Thoughts By Susan May

These are a few things parents should know who have a child who is chronically ill or are living with a transplanted child.

- A sick child in the family creates social, financial and emotional issues for every one. Stress is part of the whole picture. It is how you live with it that makes the difference. There is a sixty percent divorce rate for parents who lose a child. That statistic is frightening.

- Andy and I do not get upset over the little things like some people. We fight the battles that are important and save our energy for dealing with Nick. We look for the true gifts in life. We enjoy time together as a family and are grateful for the milestones Nick has achieved, like going to school, instead of being saddened by them. Each milestone represents another year he is alive.

- The bulk of our questions came around two to three days after the transplant. Parents need to ask all the questions they can while in the hospital. There is no better time. Around three to four months out, if the patient is doing well, is the time to

join a support group. Even if the one spouse will not attend, the other should go for themselves. This is a wonderful place to get questions answered, but be mindful that not everyone handles a situation the same way.

- Find a good pharmacist when your child is listed. The pharmacist needs to be a person who understands what is going on and will listen to you about your child's medications. We had to change our pharmacy because of insurance coverage at one point. We used a chain pharmacy where the same pharmacist never filled Nick's meds twice. After a year and a half we got to go back to our original pharmacist. He has caught, on more than one occasion, problems or possible issues with Nick's meds. Parents need to make sure their home pharmacy has the medications that are needed before leaving the hospital. After the heart transplant surgeon and the cardiologist, your pharmacist is the first line of defense to keeping a transplant patient alive. Have a great pharmacist, I do.

- Cyclosporine is a major problem to get in most pharmacies. It is not a medicine that is kept on the shelf because of its cost and there is not a huge demand for it. The main places that do have it are large teaching hospitals but

they do not want to issue it to an outpatient.

- On one vacation I hunted for Imuran in Key West, Florida for an entire afternoon and was unable to find it. Imuran is an older medicine and usually not stocked. I located it on the mainland a day later.
- Nick never takes herbal supplements because they can interact negatively with his regular meds. A transplanted person should always ask their doctor before taking herbs while on other medications.
- I make a point of being aware of the "H" signs when traveling so that I can take Nick to the hospital anywhere. On more than one trip out of town I used the signs to direct me to the nearest hospital. Without the signs I would have wasted valuable time hunting for a hospital.
- I carry paper copies of Nick's prescriptions with me when we travel. That way I always have a way of getting his medicines without calling the coordinator.
- Being in the hospital is like being in the Twilight Zone or the Bermuda Triangle -- I want to know how to get out. It seems

Nick goes in for a simple test and gets stuck for an indefinite time. I learned to deal with the slow process of healing, and push as I could for him to go home.

- I spent a huge amount of time seeing about medical bills. I knew I had to watch them, making sure we were not over charged and checking to see that the insurance was paying their share. Reviewing bills was a full time job.

- We made an effort to give special attention to Nick's brothers and sister when they were younger. Children can experience many different emotions when they have a sick sibling. These emotions can be resentment, guilt, and jealousy, as well as pride and love. A parent must keep these in mind when dealing with the siblings. We handle these emotions by supporting them in their activities. If one child is in the band, then the whole family goes to the band concert, if another wrestles we are all there.

- As parents one of the problems is the inability to offer attention and support when the other children need it. My mother helped out in this area. She was a constant by filling in for me when Nick was at the hospital. We make the effort to tune into our children in order to know what is going on with them, and

listen to what they have to say. We are not always good at this but we do try.

- I have tried to include Drew, Mary Beth, and Zach when Nick got to do something fun at the hospital. They have gone to parties, parades, and baseball games sponsored by the hospital. I never wanted everything to be just about Nick. I am not sure what effect having a brother who is so sick has had on them but as far as I can tell they are well-adjusted. As they have matured I know they are more aware of Nick's illness and understand death more clearly.

- Sometimes because of financial issues with a sick child another might not be able to have what they want. An example could be not having money to be able to go off to college, or to get the car of their choice. Each problem must be handled case by case; sometimes there is no way around resentment.

- All our children have chores including Nick. Everyone makes up our family and should have a part to play even if they have a medical problem. It is important for all the children to see themselves as team members.

- We try to be fair disciplinarians. This is hard enough when

there are no sick children involved. We cannot win this battle, we just do the best we can.

- Children will behave like their parents. Andy and I have tried to give our children strong coping skills, so they understand that you can cry and survive. We let ours know when we are afraid. We talk to them about the situation making an effort not to scare them, but explaining to them what they can do to help and give them the facts honestly. I like to be up front about the problem. Coloring books, literature, and hospital visits can be helpful in siblings understanding better what is happening. I have asked Dr. Vincent more than once to show Nick's brothers and sister something in the hospital so they know what is being done.

- When Nick got older we talked to him about his condition and Procedures being done to him. He had to learn to face his medical problems and be proactive in them. I read Death Be Not Proud which was written by a father about his son who had cancer. This book was written years before people survived cancer. My impression was that the parents were to scared to talk to their child about his illness and death. Up until just a few days before the youth died he had no idea how sick he was. I could not believe how unfair they were to him. He

had the right to know.

- I realized many years after Nick was transplanted that in the beginning I told anybody that I even had a passing conversation with that Nick had had heart surgery and later a heart transplant. I am not sure why I did this. Maybe for shock value, or I thought it defined part of who I was. I would introduce myself by saying, "I'm Susan May and I have four children and the last one has had a heart transplant." I guess I wanted people to ask me about Nick. I was proud of how well he was doing. It was my opportunity to share that transplants work.

- After years of living with Nick's condition I still wake up at night with worries over his health. These thoughts are not with me every waking minute.

- One of the ways I cope is by working through organizations like Lifelink of Georgia and the Georgia Transplant Foundation telling people about the need for organs. Another is by reading and listening to what is going on in the field of transplantation. I watch movies that come out about transplants so that I can answer questions with confidence. I stay involved in issues that have to do with donation, and I take advantage of media opportunities. I write to newspapers, magazines, and TV

stations when they say something positive or negative about organ transplants. I speak out.

- Andy and I were already organ donors by signing our driver's licenses before Nick needed one. We did not have to adjust to the idea. Many parents have to grasp the larger concept, before they can consider a transplanted organ for their child.

- A friend once told me that people tolerate a sick child, but do not like a spoiled sick one. There is truth to that statement. I have always encouraged Nick to live as normal of a life as possible. Part of that is participating in life, by doing chores, playing sports, and being responsible to himself and others. I believe part of mine and Andy's job in raising Nick is to see that he understands his responsibility to others through sharing his story. He is learning as he grows to support children who are in the same situation.

- Our goal for Nick is for him to be as happy as possible and to enjoy each day to its fullest. An organ transplant should not be used to just keep someone alive. It should be done in order for a person to live a full life.

- I have learned to be realistic about Nick's abilities. He did not feel comfortable riding a bike until he was eleven, but he found he loved it. He did not want to water ski when I thought he should, but learned when he was ready. Physical abilities did not come as easily for him as others his age.
- From the practical side Nick needs to know how to listen to his body. He has to understand the importance of taking his meds. He needs to learn to speak up and ask questions in order to find out all he can about his care and his body. Making the most of every day and staying close to his family and friends is a major part of living a full life. The most important of all is having faith in God.
- I keep Nick's medicines stocked and now he lets me know when they are running out. I urge him to eat right. The transplant diet is generally the way we all should eat. I try to teach that by example. We encourage Nick to be active in some lifetime sport so he will get exercise as an adult.
- Finding doctors and a hospital we could trust was important. You need to believe in them. We had to make sure we understood what the hospital staff was telling us. I

learned to repeat what the doctors said back to them. I wrote questions down so that time was not wasted trying to remember what I wanted to ask. Ask questions - it is your right to know, plus you are paying the doctor to talk to you. If he does not, find a new one. Ask the questions that will help you get back to life after the transplant.

- I know I am biased, but Nick has the finest doctors and nurses in the world. It is their job to know what to do. I appreciate their God - given talents. A second opinion is good, second guessing is harmful to both your state of mind and your child's care. I believe I would feel the same way if all had not gone well for Nick.

This is what Nick should strive for:

"The ultimate way of saying thank you to your donor is to live life to the fullest. Smell the flowers, enjoy your family, give back to others, hug someone, give all you can back. Tell about your transplant. Share your story. The miracle of a transplant may encourage others to donate. You may help save someone else life. Count the single minutes, hours, days, week, months and years. Cherish the holidays, weddings, birthdays, trip graduations, new jobs because the donor offered the gift of life."

-unknown.

This is the concept I hope Nick grows to comprehend. It is the attitude he needs to have about life. As he gets older he will better understand, but as his mother I can appreciate these concepts. Nick knows his new heart belongs to him, not borrowed from someone. It is a gift to be cared for and cherished.

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