

Does a Child With Disabilities = A Disabled Marriage?

By Janalee Heinemann

"Don't let one tragedy multiply into other!" warned Dr. Michael Kaback of Torrance, California in a speech at the 1985 Missouri Genetic Conference.

It helps to cope with the disabilities of our children if we can minimize the other stressors in our life and have a good support system. Often though, the "domino effect" begins gradually after the birth (or diagnosis) of a child, and over the years, we find that our relationship and our house comes tumbling down.

Does the tragedy of the disability x the personal trauma to each parent x the stress between a husband and wife automatically = a disabled family system?

When our son Man, who has Prader-Willi syndrome, was 7 and I was considering marrying his father Al (who had custody of Matt). I had to seriously contemplate the answer to that question. Fortunately, I have found the answer is no — as long as you put the same effort into yourself, your relationship and your other children as you do your child with a disability.

Although Matt is now 29, the need for a good relationship and a life of meaning and joy is still the same today as it was when he was 7. So I have been asked to reprint the following survival strategy that I wrote many years ago, which we tried to live by during the "best of and worst of" years.

Absolve Yourself Of Guilt

Parents are people too and have a right to their own lives, even if they have a child with a disability — especially if they have a child with a disability. As a person who has to deal with more daily stress than the average parent, you need to make time to replenish yourself. Notice, I said, "make time." not "find time."

With five children, two grandchildren, both working full time, and doing volunteer work, Al and I have found that we have to continually be conscientious about prioritizing our time. This may mean the car never gets waxed, the oven seldom gets cleaned and the TV never gets watched. It also means that sometimes our children get "neglected" for the sake of our personal time together.

But we feel that if we don't nurture ourselves as individuals and as a couple, we cannot joyfully give to our children.

Take A Good Look At Your Stress Factors

It helps to know where the enemy lies rather than have a

vague feeling of being bombarded from all sides. We periodically take count of what our stress factors are.

Last year, we had many unforeseen and unavoidable crises. We were able to take count and say, "No wonder we are feeling stressed — we should be!"

Then it was a matter of deciding on survival tactics and reminding ourselves that this too shall pass. This year, life is going much smoother. Now, when we are feeling stressed, we take count and usually find we are getting uptight over minor things that just aren't worth getting upset over.

Share The Parenting Role

One of the things I love about Al is how good he is with his children. Raising Matt and Sarah alone before I came into his life, he had to learn to play a strong parenting role. But I have seen fathers who are fearful of their children with PWS. It is important that mothers allow the dads the opportunity to play and bond with their children. I've seen fathers get turned off to their children because of their wives. Every time the dad picks up his child, feeds him/her, etc., the mother is constantly right there, telling him how to do it.

When a child who has a disability, there is even more potential for this to happen. One mother said it well when she wrote, "Personally, I found it very difficult (and still do) to not tell my husband what needs to be done, how rough he is, how he is really messing up 'the schedule,' etc. I have to bite my lips and turn away. I've had to leave a room when my son was crying, knowing that I could stop him in a second but it wouldn't help his Dad learn. I've watched while he threw him in the air, fearful of my son falling and yet knowing that he was giggling and having a great time and so was dad, it was my fear. When dad has the kids for a day the schedule is off but truthfully, he has learned so much and the kids have had a great time. None of this would have been possible if I had been nagging him about how to do things properly."

Savor The Good Times

It is easy to get caught up in "ain't life awful" and not really appreciate the good times (or what could be good times). We often worry about what will happen next week, next month or next year — and don't really appreciate today.

To get the most out of each day, you must be willing to be flexible. If it's a beautiful day outside, will you drop your project of cleaning out the garage to take a long walk together with the kids? Are you willing to give up your nightly TV program for an hour together in the bedroom where you can

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talk about the day over a glass of wine?

Sometimes Al and I remind ourselves and recite to each other what we are thankful for. (Of course, this is easier to do when we are out alone for dinner, and the kids, the house and the bills are at least 10 miles away!)

Don't Take Your Relationship For Granted

A good relationship won't stay good without a lot of time and effort put into it. When you have a child with disabilities, your entire life can easily become wrapped up in that child, with everyone else taking second place. It takes a lot of effort to keep a marriage nurtured, but most of us were willing to put that effort in when we were dating. Without nurturing the relationship, it is easy to forget why you got married in the first place. Besides prioritizing our time, we made a pact to never go to bed angry. This may mean a long, late night "discussion," but little hurts build into major problems if they are not dealt with. Besides, what is your alternative? A bad marriage can be the loneliest place in the world.

Get Physical

We've all read of how important it is to relieve stress by getting regular exercise. Al works out, and I swim at a local health club. We always feel better when we exercise regularly 2-3 times a week, but I have to admit that sometimes we have more difficulty prioritizing this time. (Once it was so long between visits that I forgot my locker combination.)

Physical fitness is certainly good for our health. But when I see other swimmers trying to beat the clock, instructors shaming members for their body fat and racquetball players collapsing on the floor. I wonder just how stress reducing this is when it becomes just one more area in which we have to compete or feel like failures. Personally, I have never let one of those instructors touch my body fat, and I use swimming as a way to relax and meditate. For Al, swimming isn't relaxing — just a means to keep from drowning. As for me, in this era of jogging, I am proud to say I have never run a block in my life. It's all in what turns you on and your tension off.

Speaking of what turns you on, how hard do you work at turning each other on? "Getting physical" also means touching each other a lot, holding hands, kissing and making love even if it's not Saturday night. It's amazing how many couples feel it's okay to touch in front of the kids, but not okay to snuggle and hold hands in front of them!

Couples often are at different places sexually when they are in the early stages of grieving. Typically, the husband finds comfort in making love, where the wife may have diminished sexual desire. It is important to address your different sexual

needs openly and come to an open agreement on what you can do to meet each other's needs.

Cry A Little, Laugh A Lot, Be A Little Crazy

Living with any child with special disabilities, there are going to be times when life seems overwhelming and you're hurting — for yourself and your child. It's okay to cry. It's even more okay to cry together.

But even in the worst of situations, you can often find things to laugh about. What's funny about Prader-Willi

syndrome? Come to a PWS support meeting or conference and you will find out. The day your child got caught with his pockets full in the Brach's mixed candy section of the grocery store may not have been funny at the time, but can bring shared humor at a group meeting.

I have worked with people whose children have cancer. There is laughter at their meetings also. A sense of humor is essential to one's mental health. It helps to be able to laugh at yourself and with others. (I do want to note here that this usually only becomes possible with time. Young parents are often shocked at what parents of older children with PWS can laugh about.)

Take Control Of Your Life Again

When you have a child with Prader-Willi syndrome who is sometimes out of control, and whose destiny you can't control, it is easy to lose a sense of control yourself.

No, life has not been fair and there are some things that wallow in how unfair life has been to you and your child, or you can pick yourself up and decide how to make the best of your situation. What can you do differently? How can you find some happiness in each day? How can you give some happiness each day? Do you forgive yourself when you have not handled your child as well as you would like? Do you forgive your spouse when he/she does not handle your child as well as you would like? Do you take your anger over the situation out on those you love? What can you control — and what is beyond your control?

Our personal strength and the strength of our relationship can grow out of difficult situations.

Remember, the best thing you can do for your child is to have a good relationship with your spouse and to show your children how to enjoy life. God has not put you on the earth to suffer with your child, but has given you a challenge to find your way above the suffering.