

Life Lessons Learned In Holland

My most selfless acts have been imparted to Benjamin, not because I am by nature a selfless person but because he came into this world needing that of me. By the same token, my most selfish thoughts were a result of him needing me so much. A result of the requirements of his life being so intertwined with the duties of mine.

I have learned that I can be both selfless and selfish and still be true to Benjamin and myself. But that I will have guilt over both.

Life Lessons

Over the years I have taken numerous classes in early childhood development, worked in daycare centers, been a nanny, and operated my own home daycare. Not to mention the 9 “active duty” years I have put in raising my own children. Some days I feel I do pretty well at this parenting thing. At least I work hard at it. But many days...

I remember watching a movie entitled “Hanging Up” starring Meg Ryan, Diane Keaton, and Lisa Kudrow. It was about 3 sisters and their relationships with; each other, significant others, and their (divorced) parents.

I remember Meg Ryan’s character asking her mother why she left. The mother said, “It turned out to be not reason enough.” She was referring to being a wife and mother not being as personally fulfilling as she had always been led to believe it would be. Which reminds me of another quote I heard years ago about the “fairy tales little girls are fed up for breakfast.”

There are people for whom parenting is absolutely everything. They love kids, love being parents, wouldn’t change anything, never seem resentful of the all-consuming nature of it all...and I hope to God they are being honest with themselves and the rest of us.

As for me, I love my children, more than I would have ever believed possible. I like parenting...though perhaps not as much as I thought I would. And I have moments now and again, when the relentless demands of parenting pull me so far down that the joys of parenting don’t seem to “be reason enough.”

But...in between those moments I experience slices of life.

Yesterday Matthew and I packed a picnic and went to a park to play with friends. Now, I like to think that I’m the kind of person who would go to a park in the middle of the day, in the middle of the week, for no other reason than that the weather was beautiful. But maybe I’m not. Maybe for me to be that person, I needed there to be a child’s wish to do so.

Today Matthew and I set up a pup tent in the backyard. We spent the afternoon reading books and listening to the breeze flap the tent walls. It was lazy and

peaceful and self-indulgent. It was also something I would never think of doing had I not been inspired by a young child.

It turns out my children are my work and my recreation. My aggravation and my contentment. My craziness and my common sense. Too, they are my heart, my soul, my creativity and the very best parts of me. And...sometimes...they truly are "reason enough."

Life Lessons

As families that include children who have special needs, we do not have the same freedoms that many other families take for granted. For instance, we often times do not have the freedom to come and go at will. Our days are based not only on our own schedules, but on the schedules our children must keep with various professionals, and by and large, on the schedules of those professionals as well.

For many of us, just getting out of the house takes extra planning. But getting out of the house and having a good time at the planned event, or simply finishing your errands, almost requires an Act of God.

By leaving your home, you have already deemed the destination worthy of your time. Success is hard work. The enjoyment you experience will almost always be equal to the level of your preparation. My husband and I found our outings went better if we prepared Ben to receive the new environment, and prepared the new environment to receive Ben. This statement means different things to different people. What it means to you should be based on your child's specific special needs and your expectations as a family of what is to occur that day.

In our case, Ben's health required the temperature to be neither too hot nor too cold. This made outside activities nearly impossible at certain times of the year. But, if we could insure that there would be a refuge nearby, such as someone's home, or a public building, or our van, then we were more likely to attend the event as a family and have it be as successful for us as it was capable of being.

Your child will have his or her own requirements to participating in family activities, and you as parents will have your own "tricks of the trade" to make the day go as smoothly as possible.

Life Lessons

I have always known guilt in life, and parental guilt is like no other. I have had times or situations where I've felt I've done a good job or handled something well. But most of the time I feel that I'm missing the mark, never giving enough time to

the children or letting my frustrations get the better of me until I say something in anger rather than out of love.

Recently, I have come to realize that if we can admit to ourselves that our best would be better if circumstances were better, we are then able to let go of some of the guilt. Do the best job you can with the circumstances life has given you, and allow yourself to believe that is enough. Apologize for what you have control over and learn to accept there are things no one on earth has control over.

Life Lessons

Sometimes...there is no "cure." Are you ready to accept that? It's a hard thing to do. For many of us, it takes a long time. When I think of the years with our son, Benjamin, I am often reminded of a line from a classic storybook, *The Velveteen Rabbit*. "It was a long weary time..." Sometimes we are so tired of being tired, that we actually expend more energy in search of the elusive cure. We hope that one day, soon, our child will be healthy, will be "normal". We hope that someday everything will be "fixed" because we were finally able to find the right doctor, the right medicine, the right procedure, or the right therapy. We are stuck in the "long weary time" so we need to believe that it will get better. When we can accept that we cannot cure this thing, whatever it is, life will get better. Try to spend your time and energy enhancing your child's life as it has been given to you.

Enjoy the unique and beautiful things your child has to offer to you and to this world. Prepare for tomorrow, but spend less time worrying about it. Allow your child to be lovable and livable as they are.

Life Lessons

Some lessons are harder than others. For instance, I have learned that I knew more about raising children before I actually had any of my own! I have also learned that I knew a great deal more about my child with special needs than the professionals who dealt with him.

The specialists had probably seen more children with Williams Syndrome. They had definitely worked with far more children with Cerebral Palsy than I. But they saw them for minutes at a time. They studied them from textbooks and medical journals. They lacked the practical experience of day to day living in a home setting. My training was on-the-job. It took place 24 hours per day. I could not simply "call it a day" when my shift was over...my shift was never over. I could not decide that I didn't like pediatrics or cardiology, etc. and go into some other field. I studied Ben and his needs with the determination of a professional and the passion of a mother.

However, as Mother's Day approaches, I find myself remembering how sometimes I was so busy being Ben's nurse, teacher, therapist, or advocate that I forgot to make time to be his mom.

During the first year of Ben's life, (I call it the year of adjustment) Ben, Emily and I had "Lazy Mondays." No appointments were scheduled for Monday and no one was allowed to re-schedule anything on that day. The kids and I stayed in our pajamas and in bed. I brought snacks, books and meals to the bedroom. We watched movies, played board games, took catnaps...we ignored the world and our place in it for one day. The rest of the week belonged to the world of Ben's needs but "Lazy Mondays" belonged to us. I was saddened that as Ben's therapy schedule and medical appointments increased, it became impossible to keep our day.

As parents of children with special needs, we need to remember that while tasks loom over us every day which are life saving (like feedings, medications, and surgeries) or life-altering (such as rehab. therapies, counseling sessions, or treatment programs) the first hat we should put on in the morning is that of "parent."

Life Lessons

As the holiday season approaches, my muscles start to tense. Not in a good way that may eventually allow me to meet one of my "New Year's Resolutions." Rather, this seems more an exercise in futility if it is indeed exercise at all. It begins in October, when the very first store puts up the very first Christmas decoration. I believe they mean to inspire me...to buy my way through the holiday...if nothing more...but inspire me none-the-less.

Suddenly my mind whirls with lists of "things to do." Shopping, wrapping, baking, mailing cards, school concerts, church programs, office parties, tree trimming, turkey stuffing, family pictures, house decorating, caroling... "And these are a few of my favorite things."

All of this is meant to be fun. To inspire joy. To create the memories lifetimes are made of. But the reality is that I sometimes believe standing in one place and pulling my hair out may afford me an equal amount of "seasonal bliss."

To some extent we create our stress, and then our stress creates us. There will always be things in this life that we have no control over; the diagnosis of a disability or health problem, an accident, losing a job, the loss of a loved one. Set those things aside and look at what you have left. Are there things about your life you could change if you wanted to? Would you benefit from the change, or would the effort involved to effect change outweigh the benefit?

Going financially bankrupt at Christmas does not bring one closer to capturing the spirit of the season, so work out a reasonable budget and stick to it. Over scheduling personal an/or family time can make a person grumpier than "Scrooge" so be very selective of commitments to time. One idea can be to combine the two, and allow time to be your gift.

An elderly neighbor of mine tells her children that she doesn't want their "presents" she wants their "presence." So each year they choose a project to work on for her at her home. They all show up on one day, to feast and work and play. It reminds her of when they all lived at home with her.

My husband's sister gets together with her mother-in-law and all the daughters and grandchildren for a Holiday Crafts Day. Each family is responsible for bringing the supplies for one craft project. At the end of the day, they each have several homemade ways to decorate for the season.

There are numerous ideas out there to help you have a "reduced stress" holiday. Find a few that will work for your family. Remember, do not try them all at the same time. Trying too hard to relax can be stressful in it's own right.