

WELCOME TO BEIRUT

by Susan F. Rzucidlo

“I am often asked to describe the experience of raising a child with autism-to try and help people who have not shared in this unique experience to understand it, to imagine how it might feel. It’s something like this..”

There you are, happy in your life, one or two little ones at your feet. Life is complete and good. One of the children is a little different than the other but of course, he’s like your in-laws, and you did marry into that family. It can’t be all that bad. And then one day someone comes up from behind you and throws a black bag over your head. They start kicking you in the stomach and trying to tear your heart out. You are terrified. You’re kicking and screaming you struggle to get away but there are too many of them, they overpower you and stuff you into a trunk of a car. Bruised and dazed, you don’t know where you are. What’s going to happen? Will you live through this? This is the day that you get the diagnosis: “YOUR CHILD HAS AUTISM!”

There you are in Beirut, dropped in the middle of a war. You don’t know the language; you don’t know what is going on. Bombs are dropping “lifelong diagnosis” and “neurologically impaired.” Bullets whiz by. “Refrigerator mother.” “A good smack is all HE needs to straighten up.” Your adrenaline races as the clock ticks away at your child’s chances for “recovery.” You sure as heck didn’t sign up for this and You. Want. Out. NOW! God has grossly overestimated your abilities.

Unfortunately, there is no one to send your resignation to. And you’ve done everything right in your life. Well, you tried and you weren’t caught too often. Hey! You’ve never even heard of autism before! You look around, and everything looks the same, but different. Your family is the same, your child is the same, but now he has a label, and you have a case worker assigned to your family. She’ll call you soon. You feel like a lab rat dropped into a maze.

Just as you start to get the first one figured out (early intervention) they drop you into a larger more complex one (school). Never to be outdone, there is always the medical intervention maze. And that one is almost never completed. There is always some new “miracle” drug out there. It helps some kids. Will it help yours? You’ll find some of the greatest people in the world are doing the same maze you are, maybe on a different level but a special education maze just the same. Tapping into these people is a great lifeline to help you get through the day. This really sucks, but, hey, there are still good times to be had. WARNING! You do develop an odd sense of humor. And every so often you still get hit by a bullet or bomb not enough to kill you, only enough to leave a gaping wound. Your child regresses for no apparent reason, and it feels like a hit to the stomach. Some bully makes fun of your kid, and your heart aches. You’re excluded from activities and

functions because of your child, and you cry. Your insurance company refuses to provide therapies for “chronic, life-long diagnoses” and your blood pressure goes up. Your arm aches from holding onto the phone with yet another bureaucrat or doctor or therapist who holds the power to improve or destroy the quality of your child’s life with the stroke of a pen. You are exhausted because your child does not sleep.

And yet, hope springs eternal.

And yes, there is hope. There ARE new medications. There IS research going on. There ARE interventions that help. And thank God for all those who fought so hard before you came along. Your child will make progress. And if he speaks for the first time, maybe not until he is 8 years old, your heart will soar. You will know that you have experienced a miracle and you will rejoice. The smallest improvement will look like a huge leap to you. And you will now marvel at typical development and understand just how amazing it is. You will know sorrow like few others, and yet you will know joy above joy. You will meet dirty-faced angels on playgrounds who are kind to your child without being told to be. And there will be a few professionals, and nurses and doctors who treat your child with respect and who treat you with respect and concern like few others. Knowing eyes will meet yours in restaurants and malls, and they’ll understand. They’re living through similar times. For those people, you will be forever grateful. Don’t get me wrong. This is war, and it is awful. There are no discharges and when you are gone someone else will have to fight in your place.

But, there are lulls in war, times when the bullets aren’t flying, and bombs aren’t dropping. Flowers are seen and picked. Life-long friendships are forged. You share an odd kinship with people from all walks of life. Good times are had and because we know how bad the bad times are, the good times are even better. Life is good, but your life is never normal again, but hey, what fun was normal anyway.

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